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ABSTRACT

This manual is designed to provide resource managers, advocates, and social service personnel with information about the integration of community services for persons with traumatic brain injury (TBI). The materials encompass the values of independence, productivity, and integration in the delivery of resources and services to persons with TBI. Each of the 12 informational sections begins with an outline of the goal and objectives of the included material. The beginning section provides an overview of TBI, followed by sections addressing the following issues: (1) attitudinal and language barriers; (2) employment issues for persons with TBI, including the implications of the Americans with Disabilities Act; (3) necessary supports for independent living for persons with TBI; (4) housing for persons with disabilities, including funding and legal issues; (5) Social Security Administration programs for persons with TBI; (6) state vocational rehabilitation agencies and their implications for persons with TBI; (7) community based services and resources for persons with TBI; (8) substance abuse issues for persons with TBI; (9) sexuality and brain injury; (10) a checklist for writing neuropsychological reports in functional terms for vocational rehabilitation; and (11) motor vehicle driving evaluation issues for persons with TBI. An appendix includes information summary sheets designed for slide presentations. (CR)

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Integrating Community Resources

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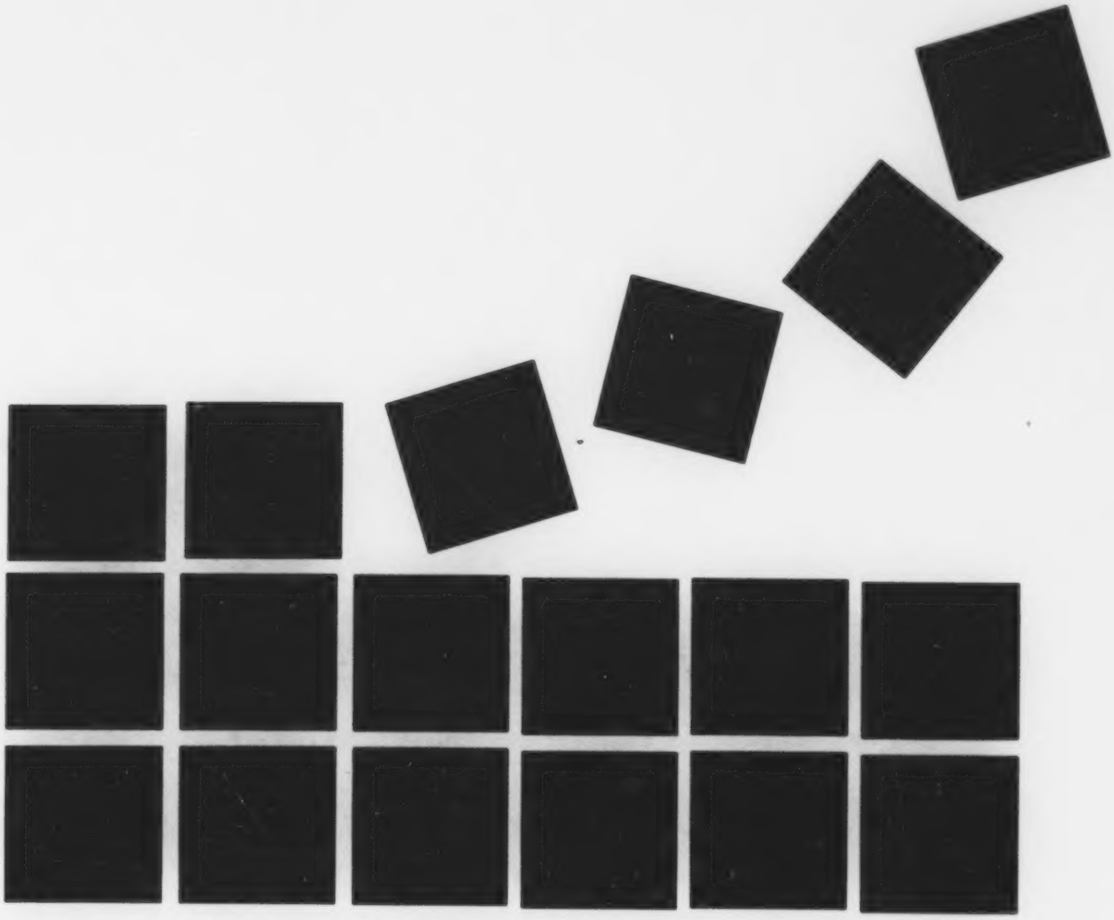
Integrating Community Resources



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Introduction and Mission Statement

The purpose of this manual is to provide resource managers, advocates, and social service personnel with information about community integration issues specific to persons with traumatic brain injury (TBI).

These materials encompass the values of independence, productivity and integration in the delivery of resources and services to persons with TBI. Case/resource managers, independent living center counselors, vocational rehabilitation counselors, health professionals, and all others who provide services to persons with TBI and their families will be encouraged to promote these values into the delivery and expansion of appropriate community based resources and services. They will become more sensitive to barriers, both physical and attitudinal, that persons with brain injury and their families encounter in seeking resources/services. Strategies for minimizing these barriers will also be emphasized.

In addition, they will learn of methods for promoting injury prevention and will be encouraged to implement them.

Section A

Understanding Traumatic Brain Injury

Understanding Traumatic Brain Injury

Goal

Traumatic brain injury (TBI) has become a leading cause of death and disability, particularly among our youth. With the increasing sophistication of medical management, the rate of survival is increasing; however, the problems associated with traumatic brain injury are frequent and poorly understood. Despite the common occurence of brain injury, the professional community is just beginning to address the unique and special rehabilitative needs of persons who survive trauma to the brain. Knowledge of the consequences of TBI sets the stage for defining appropriate services.

Objectives

1. To explain basic neuroanatomy of the brain.
2. To become familiar with ongoing medical concerns in the field of traumatic brain injury.
3. To recognize pre- and post-injury factors influencing recovery.
4. To identify common problems associated with TBI.

Selected Resources for Understanding Traumatic Brain injury

Articles

Ewing-Cobbs L, Fletcher JM. Neuropsychological Assessment of Head Injury in Children. Journal of Learning Disabilities. 1987; 20(9):526-556.

Books

Kreutzer J, Wehman P. Community Integration Following Traumatic Brain Injury. Baltimore, MD: Paul H. Brookes; 1990.

Selenick R, Ryan C. Living With Head Injury: A Guide for Families. Washington, DC: Rehab Hospital Services Corporation; 1991.

Williams JM, Kay T, eds. Head Injury: A Family Matter. Baltimore, MD: Paul H. Brookes; 1991.

Videos

Journey From Flanders and Broken Rhymes. Transitional Living Community at Galveston, 1528 Post Office Street, Galveston, TX 77550.
(800) TLC-GROW

All The King's Horses And All The King's Men.TBI-NET, The Mount Sinai Medical Center Department of Rehabilitation Medicine, Box 1240, One Gustave L Levy Place, New York, NY 10029-6574.
(212) 241-7917

Organizations

National Head Injury Foundation, Inc.
1776 Massachusetts Avenue, NW
Suite 100
Washington, DC 20036
(202) 296-6443
Fax: (202) 296-8850
Helpline: (800) 444-6443

Southwest Regional Brain Injury Rehabilitation and Prevention Center
4007 Bellaire Boulevard
Suite EE
Houston, TX 77025
(713) 666-9550
Fax: (713) 668-5210

The following telephone numbers can be used to reach the state chapters of the National Head Injury Foundation. If the number is no longer correct, check with the National Head Injury Foundation for the current number.

Alabama: (205) 328-3505, (800) 433-8002 (in state)
Arizona: (602) 326-2872, (800) 432-3465 (in state)
Arkansas: (800) 235-2443
California: (310) 803-4418
Colorado: (303) 730-7112, (800) 955-2443 (in state), Fax: (303) 730-7112
Connecticut: (203) 721-8111, (800) 669-4323 (in state)
Delaware: (302) 654-7705
Florida: (305) 786-2400, (800) 992-3442 (in state), Fax: (305) 786-2437
Georgia: (404) 727-5588, Fax: (404) 727-5895
Illinois: (708) 485-2080, (800) 284-4442 (in state)
Indiana: (317) 356-7722
Iowa: (319) 291-3552, (800) 475-4442 (in state)
Kansas: (816) 842-8607, (800) 783-1356 (in state), Fax: (816) 842-1531
Kentucky: (502) 899-7141
Louisiana: (504) 558-0051
Maine: (207) 626-0022
Maryland: (410) 747-7758, (800) 221-NHIF (in state), Fax: (410) 747-7759
Massachusetts: (508) 795-0244, (800) 242-0030 (in state)
Michigan: (313) 229-5880, (800) 772-4323 (in state), Fax: (313) 229-8947
Minnesota: (612) 644-1121, (800) 669-MHIA (in state), Fax: (612) 644-4418
Mississippi: (601) 981-1021
Missouri: (314) 893-2444
Montana: (406) 657-2077, Fax: (406) 761-5110
Nebraska: (402) 761-2781, (800) 743-4781 (in state)
New Hampshire: (603) 225-8400
New Jersey: (908) 738-1002, Fax: (908) 738-1132
New Mexico: (505) 889-8008, (800) 279-7450 (in state)
New York: (518) 459-7911, (800) 228-8201 (in state), Fax: (518) 482-5285
North Carolina: (704) 332-9834, (800) 377-1464 (in state), Fax: (704) 334-0058
North Dakota: (701) 281-0527, (800) 279-6344 (in state), Fax: (701) 281-3878
Ohio: (614) 481-7100, (800) 686-9563 (in state), Fax: (614) 481-7103
Oklahoma: (405) 556-0147
Oregon: (503) 689-7310
Keystone State: (717) 540-9215, (800) 24-KSHIF (in state), Fax: (717) 657-8265

South Carolina: (803) 533-1613, (800) 767-9701 (in state), (803) 536-6632
Tennessee: (615) 264-3052
Texas: (512) 467-6872, (800) 392-0040 (in state), Fax: (512) 467-9035
Utah: (801) 484-2240, (800) 231-8442 (in state), Fax: (801) 467-3052
Vermont: (802) 446-3017
Virginia: (804) 355-5748, (800) 334-8443 (in state)
Washington: (206) 451-0000, (800) 523-LIFT (in state)
West Virginia: (304) 766-4892, (800) 356-6443 (in state), Fax: (304) 766-4940
Wisconsin: (414) 271-7463
Wyoming: (307) 473-1767, (800) 244-4636 (in state), Fax: (307) 266-6957

Traumatic Brain Injury 101:
An Overview of TBI

by

Diane M. Jones, MEd

What Is Traumatic Brain Injury?

A head injury refers to any injury to the head, usually as a result of an accident. It is a general term indicating damage to the head, including the scalp, the bones of the skull, face or jaw or to the contents of the skull. Brain injury more specifically indicates damage to brain cells that causes temporary or permanent interruption in their functioning. Most serious brain injuries occur in younger individuals and about half of these are the result of motor vehicle crashes. Thus, traumatic brain injury (TBI) is the name used when brain cells are injured by some type of external physical force, such as when the head strikes the windshield or is struck by an object such as a baseball. Because the brain controls and coordinates the activity of most of the systems of the body, many functions of the body can be affected by a brain injury. Although the brain has an impressive potential for recovery, it is impossible to predict how much recovery each individual will experience.

Brain injuries vary greatly in severity. Many people with TBI have problems involving the brain's ability to move different parts of the body or perceive sensations correctly. Often, these problems diminish over time with appropriate therapy. However, after a serious brain injury, problems of attention, memory, motivation, decreased ability to make judgments and personality changes persist. These changes are often the most difficult to deal with for friends, family members and teachers.

The Lobes Of The Brain

There are four major lobes in the brain. The frontal lobes serve as the "master control panel" for the brain. They link and integrate all components of behavior at the highest level by helping us organize, plan and solve problems. Emotional and social adjustment and impulse control are localized here. Injury to parts of the frontal brain may cause an inability to move part of the body or the whole side of the body, speech may become halting, disorganized, or be stopped except for single, explosive words. Personality may change. Social rules of behavior may be disregarded.

The temporal lobes, located behind the frontal lobes, perform significant functions associated with perception and recognition of verbal material, memory, hearing, taste and smell. Temporal lesions may lead to seizure activity, difficulty in screening out distractions, and disorders in new learning and short-term recall.

The parietal lobes process incoming sensory information. With an injury to this area, one may lose sensation on parts of the body, become disoriented or become easily lost or confuse left and right. Injury may also produce disorders in the recall of long term memories, reading, writing or math calculations. Such individuals may also treat a leg or arm as though it did not belong to them.

The occipital lobes are located at the back of the brain and process visual information. Damage to this area may result in "blindness" to part or all of the visual field. Some individuals may have problems recognizing objects, words or other information perceived through sight.

Deeper structures in the brain (ie, the brain stem) serve the more primitive functions we often take for granted. Respiration, blood pressure, heart rate, basic arousal, swallowing and breathing are all functions of the brain stem and surrounding tissue.

Because memories are stored in various places in the brain, this system can be disturbed by damage to any area of the brain. Generally, injuries to the brain disrupt recent memories more than memories that have been stored for long periods.

Types Of Brain Injury

Brain injuries occur in many ways. Trauma is a common cause of brain injury. Motor vehicle crashes, falls and blows to the head can all lead to significant impairments of cognitive functioning. Rapid acceleration or deceleration of the head can stretch and tear nerve fibers. The typical early response of the brain to trauma is swelling.

Brain tissue may bleed. A collection of blood in the skull is called a hematoma, and can cause serious impairments and threaten life. A hematoma may swell shut the blood vessels that supply blood to the brain, or cause pressure on brain cells.

Anoxic accidents such as drowning or having the heart stop for a time cause the brain to be deprived of oxygen. Anoxia usually affects the entire brain, leading to widespread brain damage.

A stroke (cerebrovascular accident) is caused by a blood vessel in the brain bursting or becoming blocked so that it can no longer supply blood to an area of the brain.

Tumors can lead to damage of brain cells. They are often detected when they grow to the point of displacing other tissues via pressure. When neurosurgery is utilized to remove brain tumors, the resulting loss of brain tissue frequently results in significant impairment in function.

Incidence And Epidemiology

Each year more than 500,000 persons sustain traumatic brain injuries severe enough to require hospitalization. In fact, a brain injury occurs every 64 seconds of every day somewhere in the United States. Injury to the brain is more common than multiple sclerosis, spinal cord injury and muscular dystrophy. Research has shown that young males are the most frequently injured members of our society, especially during the months of June through September. Consumers will be billed an estimated $4 million over a five to ten year period for the medical and rehabilitation services needed by a person surviving TBI. Approximately $25 billion is spent annually in the United States for the care of persons with TBI.

The Effects Of Traumatic Brain Injury

Brain injuries almost always have some adverse effect on a person's performance of ordinary tasks. Changes may be noted in memory, complex thinking, communication skills, sensory processing or emotional functioning. It is important for family members and friends to recognize that these changes are not the fault of the person who has been injured. After experiencing a brain injury it is hard for the injured person to control all aspects of his/her behavior. The automatic controls, which typically control our impulses, are impaired by the brain injury and may allow behaviors to surface which annoy or anger those around the individual.

Physical impairments such as difficulty in walking or altered speech patterns are easily recognized by the general public. Less easily recognized are reduced stamina, seizure disorder, headaches and hearing or vision losses.

As a result of the structural damage to the brain, changes in cognitive functioning may alter the way in which information from the environment is acquired and used. Every brain injury presents a different profile of cognitive changes. There is also great variability in the level of ability in cognitive areas. This variability and changing nature of cognition make the individual with a TBI significantly different from other more recognized disabling conditions. Common gaps in cognitive functioning include: impaired attention and concentration, impulsivity, disorders in memory, inadequate organizational skills, limited problem solving abilities, slowed processing speed, and disorientation and confusion.

Traumatic brain injury generally has a pronounced impact on behavior, as well. Additionally, the individual's cognitive impairments may be reflected in behavior and complicate the management techniques necessary. Typical behavior sequelae include: depression, denial of impairments, inappropriate social behaviors, difficulty interpreting the thoughts and intentions of others, anger and disinhibition.

Rehabilitation

The process of rehabilitation is to help the individual reach maximum potential following a brain injury. Much of the recovery will take place in the first six to twelve months after the injury occurs; however, recovery continues to occur for months and even years, but at a slower rate. Little is actually known about the mechanisms of recovery. How much recovery will occur after a brain injury is difficult to predict. Many factors influence recovery, including general health, age, the location and severity of the injury, immediate care and preinjury personality and intellectual functioning. The speed with which recovery occurs is also unpredictable and can go on for years. Research findings suggest that immediate medical care and cognitive rehabilitation result in better recovery of function.

Understanding Traumatic Brain Injury: A Slide Presentation

A copy of the slide presentation produced by the Texas Head Injury Association is located in the Appendix (pages M.1 - M.23) of this manual. The reader is encouraged to use these illustrations for preparing slides or transparencies and sharing this information with a larger audience.

References

Bigler E, ed. Traumatic Brain Injury: Mechanisms of Damage, Assessment, Intervention, and Outcome. Austin, TX: Pro-Ed Inc; 1990.

Colorado Head Injury Foundation. A Regional Family Guide to Traumatic Brain Injury. Denver, CO: The Colorado Trust and The Rocky Mountain Regional Brain Injury Center; 1991.

Section B

Understanding Attitudinal and Language Barriers

Understanding Attitudinal and Language Barriers

Goal

This section provides information on the impact that attitudes have had on people with disabilities through the centuries, and how current efforts are underway to eliminate one of the greatest barriers to living independently in the community. It is not enough to understand the history of prejudice, but one must become aware of one's own fears and biases, and subtle uses of language that can either promote the movement towards equality, or perpetuate the myths that persist in modern day society.

This section also gives an overview of the independent living movement and discusses specifically some of the issues that people with traumatic brain injury encounter as they pursue independent living goals.

Objectives

1. To discuss the roots of attitudinal barriers that confront people with disabilities on a daily basis.
2. To explain how social values and norms negatively impact the choices and options available to people with disabilities.
3. To describe the independent living movement and how persons with traumatic brain injury are included.

Selected Resources for Understanding Attitudinal and Language Barriers

Articles and Books

Buscaglia L. The Disabled and Their Parents: A Counseling Challenge.
Thoroughfare, NJ: Chas B. Slack; 1975.

Goldman CD. Attitudinal Barriers. Disability Rights Guide. Kansas City, KS: Media Publishing; 1990.

Goodwin R. What Really Limits Us? Elevating Everyone Else's Expectations.
Rehabilitation Gazette. June 1990; 30.

Pacer Center. It's the 'Person First' - Then the Disability. PACER Center, Inc; 1991.
4826 Chicago Avenue South, Minneapolis, MN 55417.

Koehner D. Changing Attitudes: An Examination. Disability Rag. Louisville, KY; 1983.

Perspectives Network, 7205 Pullman Place, Suite 150, Mobile, AL 36695-4322.

This Brain Has a Mouth, 61 Brighton Street, Rochester, NY 14607.

Tonsing-Gonzales L. Natural Supports and the Paradigm Shift. Proceedings from the Second Annual Common Threads Conference. Missoula, MT: Rural Institute on Disabilities; 1992.

Woodward JR. Getting Rid of 'Special'. The Disability Rag. Louisville, KY; Nov/Dec 1991.

Videos

The Day After. Doug Koehner, New Vistas Independent Living Center, 2005 South Pacheco,
Suite 105-A, Santa Fe, NM 87501.
(505) 471-1001

It's a New Day. South Bay Mayor's Committee on Employment of Persons with Disabilities,
Manhattan Beach, CA.

Close Encounters Of The Disabling Kind. Mainstream, Inc., ADA Management Kit.
(301) 654-2400.

People

The most valuable resource for conducting a training on "Changing Attitudes" is having a panel of people with disabilities discuss their personal experiences with prejudice. Contact a local independent living center or a local/state head injury association for help in identifying speakers regarding traumatic brain injury.

Changing Attitudes: Addressing the Greatest Barrier to Independent Living

by

Linda Tonsing-Gonzales, MA, and George Bolden

Introduction

Addressing the barriers to independent living is a vast, complex, and all-encompassing issue for the person with a disability living in American society today. Barriers include, but are not limited to, inadequate and underfunded services, inaccessible environments, segregated programs, and lack of opportunities to pursue educational and meaningful careers.

Even more insidious than the obvious barriers listed above, is the subtle societal influence that permeates the thinking of persons with, and without, disabilities. Regardless of disability type, there are negative attitudes, stereotypes, myths, language, social values and roles which cut across race, economic status, and gender.

To even begin to address the obvious - transportation, unemployment, attendant services, skills training, social activities - is pointless until consideration is given to the template upon which the "disability model" has been built.

The Roots Of Prejudice

How is it that this society has come to hold certain values and attitudes about people whom we perceive as different? Where do all the myths come from that associate disability with being sick, dependent, incapable and feared? Each member of society becomes ill at some time, is in need of help from another, or becomes unable to accomplish various tasks. When a disability is added, the person with a disability is somehow devalued and these aspects often define the total person.

The roots of prejudice against persons with disabilities go back many centuries. Early Greeks, Christians, and Hebrews viewed those with physical or mental disabilities as inferior, possessed by demons, or punished by God. Such persons were isolated or shipped out to sea. In the Middle Ages, persons with disabilities were often relegated to an active beggar society or housed away in large asylums.

In more recent times, with the advance of medicine and technology, a whole new field has evolved as professionals have received training to work with persons with disabilities. However, the person who has the disability is often viewed as being in a dependent position, and the "professional" (be it medical or rehabilitation) is the expert in the relationship. That context can often imply a whole set of values that the person with a disability is encouraged (or trained) to accept. The experience can be frustrating because the values of the non-disabled are not always applicable, or desirable to a person with a disability.

A healthier approach is for the person with a disability to learn what is of real value to him/her, then have the encouragement to pursue it. But a lack of trust, often rooted in fears, prevents many from letting go of status quo ideas and values about health and normalcy. A person who has a hearing impairment is often encouraged to read lips as opposed to learning sign language. Using leg braces to walk upright was viewed by many as preferable to using a wheelchair. A person with speech difficulties is often devalued and not recognized as "capable" in many areas of his/her life.

Still, a movement has begun - by, with, and of people with disabilities. A growing number of individuals are emerging who are reclaiming their right to be who they are in all their differentness.

The Disability Rights Movement

The disability rights movement is in sync with a society that has been dealing with its prejudices for well over a century. As other suppressed groups are working for community access and equality, so too, are people with disabilities. And, like other groups who are perceived as "different", the disability community is speaking out for equality and access to society. Persons with disabilities are determined to take their place in society as neighbors, workers, spouses, students, and parents. They are eliminating the stereotypes and myths. That is why language becomes so important - because words either perpetuate mind sets or they implant new concepts.

Language

"People first" language is really all that is needed to remember when talking about people with disabilities. By putting people first, the caste system of "the disabled" or "the handicapped" can be avoided. Don't put the disability before the person. It's better to say "a person with traumatic brain injury" instead of "a brain damaged child" or "he/she's brain damaged". Also, avoid using words such as "victim of", "suffered", and "confined" that are value-laden to evoke certain responses of pity or helplessness.

The Person With Traumatic Brain Injury

Fears around "letting go" of certain beliefs are seemingly justified by what we might deem "special cases". Disabilities with cognitive impairments like traumatic brain injury (TBI) are frequently viewed as "special cases" in the rehabilitation and disability fields. A whole field of rehabilitation has grown rapidly over the last ten years on the premise that TBI is "special".

The field of medical and cognitive rehabilitation of persons with traumatic brain injury has its roots in the medical system. Only in the last ten to fifteen years has technology been developed which has allowed persons who sustained severe trauma to survive. The medical model of delivery of services has developed from a parent-advocate and medical basis of care and protection, rather than a consumer-driven, independence model. Most disability groups have also evolved through similar systems, and some remain in this framework today. However, there is growing consumerism through brain injury survivor groups and cross-disability coalitions. The population with TBI are becoming increasingly active in voicing their specific needs and advocating for themselves.

Grassroots organizations such as TBI Survivor Peer Groups and Survivor Councils are developing throughout the country, and are effectively making changes within systems that affect their lives. Joining with existing cross-disability coalitions is also strengthening the base of support needed to increase resources and community living supports to all persons with disabilities.

Independent Living

The term "independent living" is frequently misunderstood. Independent living is not about living alone. It's about life, control, and choices. It is interdependence in mainstream America. It is about integrating, empowering, and becoming. It is a social movement to bring about necessary supports that facilitate involvement and independence for persons with disabilities. It is basic services to help a person with a disability get basic support and acquire basic skills and self-respect.

The independent living movement began with a handful of people at half a dozen centers around the country in the early 1970's, and has grown to over 350 centers across the nation today. The independent living phenomena has impacted almost every facet of the rehabilitation field. The ultimate goal is to seek empowerment for every person who has a disability. Due to its philosophy, services and consumer movement, the concept of independent living is on task in achieving its goals.

Summary

Changing attitudes begins with individuals. We can legislate rights, but we cannot force people to change their opinion. Due to changes in disability status as a result of civil rights movements and laws such as the Americans with Disabilities Act (ADA), perhaps the generations to come will not place a greater or lesser value on difference. In an accessible society, the differences will be more equalized and each person's worth will be measured on intrinsic values, not external comparisons.

In the meantime, individual attitudes will change as society has more opportunities to experience all types of people in all kinds of situations and environments. As workers in the field, service providers have the responsibility to foster growth and self-reliance in everyone they serve. Concepts such as conformity and adjustment can be viewed more broadly, and the focus of rehabilitation and community inclusion can be based on individual values and choices.

Changing Attitudes: Addressing The Greatest Barrier To Independent Living: A Slide Presentation

A copy of the slide presentation produced by the Texas Head Injury Association is located in the Appendix (pages M.24 - M.32) of this manual. The reader is encouraged to use these illustrations for preparing slides or transparencies and sharing this information with a larger audience.

It's the 'Person First' - Then the Disability

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4826 Chicago Avenue South, Minneapolis, MN 55417-1098

What Do You See First?

- The wheelchair?
- The physical problem?
- The person?

If you saw a person in a wheelchair unable to get up the stairs into a building, would you say "there is a handicapped person unable to find a ramp" or would you say "there is a person with a disability who is handicapped by an inaccessible building"?

What is the proper way to speak to or about someone who has a disability?

Consider how you would introduce someone - Jane Doe - who doesn't have a disability. You would give her name, where she lives, what she does or what she is interested in - she likes swimming, or eating Mexican food, or watching Robert Redford movies.

Why say it differently for a person with disabilities? Every person is made up of many characteristics - mental as well as physical - and few want to be identified only by their ability to play tennis or by their love for fried onions or by the mole that's on their face. Those are just parts of us.

In speaking or writing, remember that children or adults with disabilities are like everyone else - except they happen to have a disability. Therefore, here are a few tips for improving your language related to disabilities and handicaps.

1. Speak of the person first, then the disability.
2. Emphasize abilities, not limitations.
3. Do not label people as part of a disability group - don't say "the disabled": say "people with disabilities".
4. Don't give excessive praise or attention to a person with a disability: don't patronize them.
5. Choice and independence are important: let the person do or speak for him/herself as much as possible: if addressing an adult, say "Bill" instead of "Billy".

6. A disability is a functional limitation that interferes with a person's ability to walk, hear, talk, learn etc: use handicap to describe a situation or barrier imposed by society, the environment or oneself.

Say:	***Instead of:***
Child with a disability	*disabled or handicapped child*
Person with cerebral palsy	*palsied, or C.P., or spastic*
Person who is deaf or hard of hearing	*deaf and dumb*
Person with retardation	*retarded*
Person with epilepsy or person with seizure disorder	*epileptic*
Person who has	*afflicted, suffers from, victim*
Without speech, nonverbal	*mute or dumb*
Developmental delay	*slow*
Emotional disorder, or mental illness	*crazy or insane*
Uses a wheelchair	*confined to a wheelchair*
With Down Syndrome	*mongoloid*
With a learning disability	*is learning disabled*
Nondisabled	*normal, healthy*
Has a physical disability	*crippled*
Congenital disability	*birth defect*
Condition	*disease (unless it is a disease)*
Seizures	*fits*
Cleft lip	*hare lip*
Mobility impaired	*lame*
Medically involved, or has chronic illness	*sickly*
Has hemiplegia (paralysis of one side of the body)	*hemiplegic*
Has quadriplegia (paralysis of both arms and legs)	*quadriplegic*
Has paraplegia (loss of function in lower body only)	*paraplegic*
Of short stature	*dwarf or midget*
Accessible parking	*handicapped parking*

Getting Rid of 'Special'

by

John R. Woodward

Reprinted in its entirety from The Disability Rag; Nov/Dec 1991, p. 35.

"Special education," "special needs" and the Special Olympics: isn't it about time we got rid of them?

If we can dispense with the word "handicapped," then it's past time to stop being "special."

"Special" implies differentness and apartness. "Special" is the label on segregated programs: "special education" and "Special Olympics." "Special" is a euphemism, a word introduced by do-gooders to sugar-coat their control of our lives.

"Special" is a dangerous one to let go by, because it has an aura that attracts the media. Everybody loves the "special kids" because, gosh darn it, they're so loveable up there on that poster. A hundred major corporations support the Special Olympics, "special" Scouting and Very Special Arts. No right-thinking person would dare criticize a Special organization. (Maybe ADAPT needs to change its name to Very Special Activists.)

A television "special" signals an unusual treat. A Special Agent of the FBI has extra powers. The "daily special" is an extra value. A "special guest star" is someone considered attractive and important. Do these qualities describe your life?

"Special" infantilizes and trivializes the identify of a disabled person. If you are disabled, you are not "special", you are disadvantaged and oppressed.

When the term is used to refer to disabled people, it isn't even all that descriptive. If you didn't know that "special education" meant teaching kids with disabilities, you couldn't figure it out from that name.

Recently, some folks with developmental disabilities started a Kiwanis group here in Tallahassee. They didn't call it the Special Kiwanis; they called it the Aktion Kiwanis of Tallahassee. Now they're a nationally-accredited Kiwanis chapter, with all the rights and responsibilities that go with accreditation. They didn't need "special" because they didn't have a lot of do-gooders running things for them.

Can you imagine a day when the sponsors will let the "special" kids run the Special Olympics? What would they call it? The Empowerment Games?

We need to become as militant about "special" as we are about "handicapped" and The Jerry Lewis Telethon. Let reporters and managers of charitable organizations know that we feel the word "special" is inappropriate. If you confront them often enough, they'll get the message.

We need to deny there's anything special about being disabled, so we can stop getting "special treatment" instead of justice.

Section C

Employment Implications for Persons with Traumatic Brain Injury

Employment Implications for Persons with Traumatic Brain Injury

Goal

Information on reasonable accommodations as described in the Americans with Disabilities Act, Title I- Employment will be provided in this section. An overview of the specific accommodations needed by persons with cognitive disabilities, both in the world of work and post-secondary education, will be presented. A section on appropriate interview questions and behaviors has been included as well.

Objectives

1. To identify individuals who are protected from discrimination under Title I of the ADA.
2. To explain "Reasonable Accommodations" as they pertain to persons with traumatic brain injury.
3. To explain "Undue Hardship".
4. To provide various strategies for vocational/post-secondary education reentry for persons with TBI.

Selected Resources for Employment Implications for Persons with Traumatic Brain Injury

Articles

Parente R, Stapleton M, Wheatley C. Practical Strategies for Vocational Reentry After Traumatic Brain Injury. Journal of Head Trauma Rehabilitation. 1991; 6(3):35-45.

Books

Golden M, Kilb L, Mayerson A. Explanation of the Contents of the Americans with Disabilities Act of 1990. 1992.

Guth, M. Accessing Community Resources: Discharge Planning. In: Burke W, et al, eds. The HDI Professional Series on Head Injury. Houston, TX: HDI Publishers; 1988.
(800) 321-7037

Wehman P. Supported Employment, Model Implementation and Evaluation. In: Kreutzer J, ed. Community Integration Following Traumatic Brain Injury. Baltimore, MD: Paul H. Brookes; 1990.

Video

Close Encounters of the Disabling Kind. Mainstream Inc., ADA Management Kit.
(301) 654-2400

Organization

Disability Rights Education and Defense Fund, Inc., 2212 Sixth Street, Berkeley, CA 94710.
(415) 644-2555
TDD: (415) 644-2629

Americans with Disabilities Act: Title 1 and Persons with Traumatic Brain Injuries

by

Mike Ward, MS, CCC-A, and Linda J. Courtney, LMSW-ACP

Persons with traumatic brain injuries, like all persons with disabilities, are protected from discrimination in the areas of employment, state and local government services, public accommodation, transportation and telecommunications under the Americans with Disabilities Act (ADA). Although traumatic brain injury (TBI) is not specifically mentioned in the regulations of the Americans with Disabilities Act, persons with a TBI often have disabilities that affect the major life activities that include caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning and working.

In many instances, the disabilities of persons with a traumatic brain injury are not readily visible. Society, in general, often relates disability to persons in wheelchairs. As a result, many people with non-visible disabilities such as TBI face discrimination, especially in vocational endeavors. Many are excluded from jobs that they are qualified for because of barriers in the workplace. The ADA recognizes that these barriers are a form of discrimination, and for this reason the ADA requires **reasonable accommodations** as a means of eliminating barriers that prevent or restrict employment opportunities for otherwise qualified individuals with disabilities.

Title I: Employment

The section of the ADA that addresses employment issues is Title I - Employment. Specifically, Title I has two accessibility requirements. These are:

- Employers with 15 or more employees may not discriminate against qualified individuals with disabilities (effective July 26, 1994).
- Employers must reasonably accommodate the disabilities of qualified applicants or employees, including modifying work stations and equipment, unless undue financial hardship would result.

Persons with disabilities are restricted in employment opportunities by many kinds of barriers. Some face physical barriers that restrict getting into and around a work space or the use of equipment needed to do a job. Others are excluded because of inflexible work schedules, environmental distractions, and other cognitive/psychosocial factors. Many persons with disabilities are limited in their employment opportunities by unfounded fears, stereotypes, and misconceptions about job performance, safety, absenteeism, costs or acceptance by co-workers and customers.

Under the ADA's Title I, if a person with a disability is qualified to perform the essential functions of a job **except for** functions that cannot be performed because of related limitations and existing job barriers, an employer must try to find a reasonable accommodation that would enable this person to perform these functions. The reasonable accommodation should reduce or eliminate the unnecessary barriers between the individual's abilities and the requirements for performing the essential job functions (from the Technical Assistance Manual on the Employment Provisions (Title I) of the Americans with Disabilities Act, p. III-2).

The ADA provides protection from discrimination on the basis of a disability. This protection is provided to people with disabilities that may be interested in obtaining employment, but it also applies to individuals with or without disabilities who may be currently employed. Employees are protected through the ADA from termination simply because they may become disabled, for example. The ADA requires employers to consider reasonable accommodations for such employees in an effort to allow them to maintain their employment. The ADA requires employers, in cases where an individual can no longer perform the essential functions of a job, to consider other employment positions that an employee may be able to perform within the organization with or without reasonable accommodations.

In addition, it is necessary for employers to consider assistive/adaptive technologies as a reasonable accommodation that may allow an employee (or an applicant) to perform the essential functions of his/her position. In the event an employer may find the expense to be too great to provide the needed technology, the employer must make contacts to determine other funding alternatives, such as the state vocational rehabilitation agency, that may be able to assist with some or all of the expense.

If no other funding support can be identified, the employer must provide the employee (or applicant) the option of paying for some or all of the technology himself/herself, in order to maintain employment. Current employees with disabilities are protected from discriminatory practices that might keep them from participating in training or other advancement. ADA provides protection for people with disabilities after going to work and provides protection to those employees who may become disabled while employed.

Reasonable Accomodations

"Reasonable accommodation" is a modification or adjustment to an essestial function of a job, the work environment, or the way things usually are done that enables a qualified individual with a disability to enjoy an equal employment opportunity. An equal employment opportunity means an opportunity to attain the same level of performance and/or to enjoy equal benefits and privileges of employment that are available to a similarly-situated employee without a disability. The

ADA requires reasonable accommodation in three aspects of employment:

1. **To ensure equal opportunity in the application process.**
2. **To enable a qualified individual with a disability to perform the essential functions of a job.**
3. **To enable an employee with a disability to enjoy equal benefits and privileges of employment.**

Persons with traumatic brain injury are often affected adversely by barriers in the above mentioned arenas of application, essential job duties and enjoyment of equal benefits and privileges. Listed below are some examples of reasonable accommodations for individuals with TBI.

Reasonable Accommodations in the Application Process

- Modifications in screening and testing procedures.
- Use of alternative application forms and procedures, as needed.

Accommodations to Perform the Essential Functions of a Job

- Job restructuring to reduce the number of tasks assigned at one time.
- Using tape recorded or written instructions.
- Reassignment of a current employee who has sustained a TBI to a vacant position for which the individual with TBI is qualified.

Accommodations to Ensure Equal Benefits of Employment

- Making training opportunities available/accessible.
- Ensuring that all company-sponsored activities are accessible to persons with TBI.

Often these accommodations are very inexpensive, if not free. The person with TBI and/or his/her advocate (family member, case manager, job coach) can make recommendations for the accommodations needed on the job or job interview. Other assistance is available through the Equal Employment Opportunities Commission (EEOC), vocational rehabilitation agencies, or the federally funded Job Accommodation Network (JAN).

Undue Hardship

The responsibility of an employer to provide a reasonable accommodation is limited to those situations in which it would not be an undue hardship. Undue hardship means an action requiring significant difficulty or expense; one that is unduly costly, extensive, substantial, disruptive, or that will fundamentally alter the nature of the employment. The determination as to whether a particular accommodation will be an undue hardship for a particular employer is determined on a case by case basis.

Factors to consider in determining whether a particular accommodation would be an undue hardship include:

- The nature and net cost of the accommodation needed, taking into account the availability of tax credits and deductions and/or outside funding.

- The overall financial resources of the facility(ies) involved in the provision of the reasonable accommodation; the number of persons employed at such facility; the effect on expenses and resources.

- The overall financial resources of the employer; the overall size of the business with respect to the number of its employees; the number, type and location of its facilities.

- The type of operations of the employer, including the composition, structure, and functions of the workforce; the geographical separateness, administrative, or fiscal relationship of the facility or facilities in question to the employer.

- The impact of the accommodation on the operation of the facility, including the impact on the ability of other employees to perform their duties and the impact on the facility's ability to conduct business.

It is important to note that Congress clearly established that the focus for determining undue hardship under ADA guidelines should be the resources available to the employer. An employer may not claim undue hardship just because the cost of an accommodation is high in relation to an employee's wage or salary. However, if restructuring a job to accommodate an individual with a disability creates a heavier workload for other employees, this may constitute an undue hardship.

It is also the employer's responsibility to consider alternative sources of funding for reasonable accommodations before he/she asserts undue hardship based on cost. The employer must pay for the portion of the accommodation that would not cause an undue hardship if some other resource, such as vocational rehabilitation agency, pays for a portion. If the remainder would still be an undue hardship for the employer, the employer must give the individual with a disability the opportunity to make up the portion of the cost that would be an undue hardship before the employer can claim undue hardship.

A specific ADA-related tax credit and deduction is available to employers to assist with the cost of making reasonable accommodations. Tax credits are also available under the Targeted Jobs Tax Credit Program (TJTCP) for employers who hire individuals with disabilities referred by state or local vocational rehabilitation agencies, State Commissions on the Blind, and the U.S. Department of Veterans Affairs, and certified by a State Employment Services.

For more information on undue hardship, call your local Equal Employment Opportunity Commission (EEOC). This federal agency is very involved in making sure the ADA is being enforced and has been instrumental in providing training opportunities to employers about the ADA.

Recommendations

A significant amount of misinformation, myth, and fiction has been disseminated concerning the Americans with Disabilities Act. Persons with disabilities need to take the lead in educating the American public on the facts concerning the ADA and on disability itself.

Numerous education opportunities exist for training on the ADA. It is recommended that the employers as well as persons with disabilities and their advocates receive training on the ADA. There are many training programs available. One such training program is available through the Independent Living Research Utilization Project.

For more information contact:

Independent Living Research Utilization Project (ILRU)
Southwest Disability & Business Technical Assistance Center for Region VI
2323 South Shepherd, Suite 1000
Houston, TX 77019
ADA Hotline (800) 949-4232
(713) 520-0232
TDD: (713) 520-5136

The ADA is a law that encourages cooperation and collaboration on the part of persons with disabilities and the American society. Community leaders, business owners, representatives of government, service providers, and persons with disabilities need to work together to bring about the goals of the ADA. Persons with disabilities have the right to live as independently as possible within the limits of their disability, not the limits placed on them by society. Persons with disabilities must lead in the efforts to eliminate discrimination as an acceptable custom within the American culture.

Employment of Persons with TBI: Issues and Strategies

by

Linda J. Courtney, LMSW-ACP

A major community integration issue of persons with traumatic brain injury (TBI) is a high rate of unemployment. Because the disability of TBI varies from person to person in severity and extent of impairment, there has been no "cookbook" approach to competitive employment for survivors of TBI.

Guth states, "The variability among survivors of TBI is often greater than that of other disability groups, which compounds the problem of rendering the appropriate service (resource) at the appropriate time. The **most significant barrier to survivors of TBI** receiving appropriate services through existing community networks is the unique combination of cognitive and behavioral sequela resulting from even so-called minor brain trauma."

The following is a list of physical, cognitive and behavioral impairments that could result from a traumatic brain injury. Again, it is extremely important to know that not every person with a TBI will have every impairment. Many will have only a few problems which will vary in severity from person to person. It should also be noted that each person with a TBI also has capabilities that can be drawn upon to achieve successful employment outcomes.

Potential Deficits Resulting From TBI

1. Physical Impairments:
    a. Disturbance of gait
    b. Overall balance
    c. Vision
    d. Speech
    e. Hearing
    f. Gross and fine motor control
    g. Seizure activity (full range from grand mal to seizure activity that would generally be characterized as "behavioral problems").
2. Cognitive Impairments:
    a. Difficulties with attention and concentration
    b. Memory deficits
    c. Information processing abilities
    d. Language and general conceptualization.

3. Executive Function (ability to engage in independent, purposeful and self-serving behavior):
    - a. Formulating goals
    - b. Planning/problem-solving
    - c. Carrying out the plan
    - d. Evaluating performance
    - e. Initiation action (Self starting).
4. Behavioral/Emotional Impairments:
    - a. Irritability
    - b. Agitation
    - c. Aggression
    - d. Depression
    - e. Anxiety
    - f. Confusion
    - g. Denial of deficits.

How do these impairments affect the person with TBI in the workplace? Oftentimes the impairments translate to severe barriers in getting AND keeping a job. Listed below are several problems that a person with TBI might have on the job, and some possible accommodations:

- **Problem:** Nervousness, restlessness, anxiety, reduced stress tolerance.
  Accommodations: Job restructuring, reducing visual and auditory stimulation in the workplace, routine, repetition, and structure within the work space.

- **Problem:** Memory.
  Accommodations: Use of tape recorders, checklists, cuing cards, color coded items, calendars, telememo watches.

- **Problem:** Difficulty following instructions.
  Accommodations: Checklists, peer support, job coaching, routine and structure in tasks.

- **Problem:** Complex reasoning, such as inadequate problem solving skills, errors in judgement, non-sequential thought processes.
  Accommodations: Minimize and/or simplify tasks, role playing and rehearsal.

- **Problem:** Poor motor coordination.
  Accommodations: Assistive technology, restructure work environment.

- **Problem:** Decreased strength.
  Accommodations: Assistive technology, frequent breaks.

- **Problem:** Walking.
  Accommodations: Assistive technology, modifications to the workplace.

- **Problem:** Sensory impairments.
  Accommodations: Augmentative communication, interpreters, readers, telecommunication systems such as TDD/TTY, use of large print for written materials, tape recorded information.

- **Problem:** Short temper, argumentative.
  Accommodations: Behavioral training, role playing, job coach.

- **Problem:** Seizures.
  Accommodations: Environmental modifications, training of co-workers regarding seizure precautions and post-seizure behaviors.

- **Problem:** Slow work speed.
  Accommodations: Assistive technology, job restructuring, job coaching, routine, repetition and structure in the work environment, decreased environmental distractions (visual and auditory).

- **Problem:** Poor organizational skills.
  Accommodations: Skills training, environmental engineering, written instructions for essential job tasks, calendars.

- **Problem:** Sexually inappropriate behaviors.
  Accommodations: Behavioral training, role modeling, redirection to tasks.

- **Problem:** Repeating words or actions until redirected (perseveration).
  Accommodations: Redirection to task, role modeling.

Adapted from Wehman P. Supported Employment, Model Implementation and Evaluation, *Community Integration Following Traumatic Brain Injury*. *1990.*

Oftentimes problems on the job can have their roots elsewhere in the person's life. We are all affected by the world around us, and this is no less the case with persons with TBI. Stress in any area of a person's life can negatively affect job performance. The following questions can be explored by employers/supervisors to help in locating the area(s) of stress in the worker's life and in problem solving:

- Has there been a change in job duties?
- Has there been a change of management at the company, or a new supervisor on the job?
- Is the person experiencing some difficulties at home?
- Are there socialization problems away from work?
- Are there conflicts with co-workers?

If the person with TBI is involved in a Supported Employment program, these problems may be minimized by an ongoing case management approach and direct intervention on the part of the employment specialist at the job site.

What can employers do to help the person with TBI succeed on the job? Employers can learn as much as possible about the individual's needs. A job coach sometimes can initially help the employee learn the job, and inform the employer of adaptations that are needed. Preparation of the employer through an **education process** is essential in both acquiring and keeping jobs for persons with TBI. An informed employer needs to be aware of:

- The employee's abilities and problem areas.
- Specific compensatory strategies.
- Potential environmental problems.
- Situations which could increase stress.

Can persons with TBI enter or return to the workplace, even if they have severe disabilities as the result of a traumatic brain injury? With adequate supports and informed employers, the answer is: YES!

References

Guth M. Accessing Community Resources: Discharge Planning. In: Burke W, et al, eds. HDI Professional Series on Head Injury. Houston, TX: HDI Publishers; 1988.

Parente R, Stapleton M, Wheatley C. Practical Strategies for Vocational Reentry After Traumatic Brain Injury. Journal of Head Trauma Rehabilitation. 1991; 6(3):35-45.

Wehman P. Supported Employment, Model Implementation and Evaluation. In: Kreutzer J, ed. Community Integration Following Traumatic Brain Injury. Baltimore, MD: Paul H. Brookes; 1990.

Reasonable Accommodations for Post-Secondary Students with TBI

Reasonable accommodation by definition is removal of barriers to participation. Post-secondary education institutions are now required by the ADA to provide reasonable accommodations to persons with disabilities. These may include modifications, substitutions, or waivers of courses, major fields of study, or degree requirements. Each person's disability is unique and this is especially true for persons with TBI, so accommodations must be appropriate for each individual.

Accommodations need not be made if the institution can demonstrate that the accommodation would impose an undue hardship on the operation of its program. In addition, the institution need not alter academic requirements which it can demonstrate are essential to a program of instruction.

Some examples of reasonable accommodations for persons with disabilities (including TBI) in post-secondary educational settings are:

- Assistance with registration/financial aid.
- Extended time for exams.
- Note taking, tape recorders.
- Peer support.
- Training in time management.
- Training in study skills.
- Special topic courses, if needed.
- Environmental controls for noise, distractions.
- Modified instruction style as needed.
- Qualified readers or interpreters.

Reasonable accommodations for post-secondary students are provided by an office designated to support persons with disabilities in academic settings.

To request information relating to federal funding, legislation affecting people with disabilities, or services, write or call:

Association on Higher Education and Disability (AHEAD)
P.O. Box 21192
Columbus, OH 43221
(614) 488-4972
or
U.S. Department of Education
Office of Special Education and Rehabilitative Services
Program Information and Coordination Staff
Mary E. Switzer Building, Room 3132
330 C Street, SW
Washington, DC 20202-2524
(202) 732-1241
TDD: (202) 732-1723

Americans with Disabilities Act: Resources

The Americans with Disabilities Act (ADA) was signed into law on July 26, 1990. It was described by its sponsors as "the most significant civil rights bill to pass Congress in a quarter century" and the "Emancipation Proclamation for those with disabilities".

Consisting of five major sections (or Titles), the ADA bars discrimination by both private business and state/local governments in employment, public accommodations, public services, transportation and telecommunications. These Titles include:

I. Employment.

II. Public Accommodations.

III. Transportation.

IV. State and local government operations.

V. Telecommunications Relay Services.

There are over 43 million Americans with disabilities. About one-third are employed, but many millions more are capable and willing to work. "Business leaders, service providers, labor union representatives, advocacy groups and people with disabilities working together for a change will insure the successful implementation of the ADA and the full inclusion of all Americans in Main Street USA", said Rick Douglas, Executive Director of the President's Committee on Employment of People with Disabilities.

For further information on ADA contact:

U.S. Architectural and Transportation Barriers Compliance Board
1111 18th Street, NW, Suite 501
Washington, DC 20036
TDD: (800) USA-ABLE

U.S. Department of Justice
Civil Rights Division
Coordination and Review Section
P.O. Box 66118
Washington, DC 20035
(202) 514-0301
TDD: (202) 514-0381

The President's Committee on Employment of People with Disabilities
1331 F Street, NW
Washington, DC 20004-1107
(202) 376-6200
TDD: (202) 376-6205

Equal Employment Opportunity Commission
1801 L Street, NW
Washington, DC 20507
(800) 669-4000
(202) 663-4264
TDD: (202) 663-7110

Job Accommodation Network (JAN)
West Virginia University
809 Allen Hall
P.O. Box 6123
Morgantown, WV 26506-6123
(800) 526-7234 (outside WV)
(304) 294-7186 (commercial line)

Southwest Disability and Business Technical Assistance Center for Region VI
ILRU/ADA
2323 South Shepherd, Suite 1000
Houston, TX 77019
ADA Hotline: (800) 949-4232
(713) 520-0232
TDD: (713) 520-5136

Section D

Necessary Supports for Independent Living for Persons with Traumatic Brain Injury

Necessary Supports for Independent Living for Persons with Traumatic Brain Injury

Goal

The information presented in this section will provide an overview of supports needed by persons with disabilities to live in the community of their choice. A range of options and services for community supported living specific to the needs of persons with a traumatic brain injury (TBI) will also be given.

Objectives

1. To provide information on the community supports needed by persons with disabilities.
2. To provide information on specific community supports needed by persons with cognitive disabilities.
3. To identify some funding sources for community based supported living arrangements.

Selected Resources for Necessary Supports for Independent Living for Persons with Traumatic Brain Injury

Articles and Books

Nosek M, Fuhrer, M. Independence Among People With Disabilities: I. A Heuristic Model. Rehabilitation Counseling Bulletin. 1992; 36(1):6-19.

Nosek M, Fuhrer M, Howland C. Independence Among People With Disabilties: II. Personal Independence Profile. Rehabilitation Counseling Bulletin. 1992; 36(1):21-36.

Rancino J, Taylor S. People First, Approaches to Housing and Support. In: Taylor S, et al, eds. Housing, Support and Community: Choices and Strategies for Adults With Disabilities. Vol 2. Baltimore, MD: Paul H. Brookes; 1992.

Taylor S, Rancino J, Rothenberg. A Policy Analysis of Private Community Living Arrangements in Connecticut. Syracuse, NY: Center on Human Policy; 1988.

United Cerebral Palsy Association. Access to Community Living - Medicaid Section 1930, Community Supported Living Arrangements Services (CSLA). UCPA Governmental Activities FACT SHEET. April 1992.

Vander Schaaf S. An Operational Model of Lifelong Living. Journal of Head Trauma Rehabilitation. 1990; 5(1):40-46.

Organization

World Institute on Disability
510 16th Street
Oakland, CA 94612
(510) 763-4100.

Needed Community Support Services for Persons with Traumatic Brain Injury

by

Richard Petty

When addressing the issue of community integration for persons with traumatic brain injury (TBI), one must examine the choices available. Oftentimes, TBI occurs to an adult who has been independent and living in the community of their choice. Young adults have often reached a level of independence that includes living in an apartment, involvement in relationships outside the family, and vocational/educational pursuits of their choice. Persons who have sustained a TBI in their thirties and forties also often have spouses and children, their own homes, and have not only been "independent" but also have others dependent on them.

Then, suddenly and unexpectedly this world of independence is altered. The person sustaining the brain injury and their family system are required to rearrange their lives in almost every way. The person with a TBI often must undergo extensive medical and rehabilitative care, but eventually "treatment" ends.

It has been reported, however, that most of the adults with brain injuries who were discharged to home or a long-term care institution regressed in skills. Because of limited program options and financial support, too many survivors of TBI who are still in need of supports are placed in a long-term care facility or are forced to return to situations of dependence on family members.

Oftentimes there are no services available to meet long-term needs when a family takes their injured family member back home. With sufficient supports, however, a person with a TBI can live in the community of their choice again, and often with a high level of independence. Independent living (own home or apartment), supported independent living (apartments/homes with supportive services), and family living (with parents, spouse, other family members) are now possibilities.

It is recommended that consideration be given to the array of community living assisted services proposed by the World Institute on Disability (WID), an organization working to implement community services for persons with disabilities.

Recommended Array Of Services

- Personal Services, including but not limited to, assistance with bathing and personal hygiene, bowel and bladder care (including catheterization), menstrual care, dressing and grooming, transferring, eating assistance, giving medications and injections, and operating and maintaining respiratory equipment and other assistive devices.

- Household services, including but not limited to, assistance with meal preparation, shopping, cleaning, laundry, heavy cleaning, repairs and maintenance.

- Child and infant care assistance for disabled parents.

- Cognitive services, including but not limited to, assistance with money management, planning and decision making.

- Communication services, including but not limited to, interpreting, reading, letter writing.

- Security enhancing services, including but not limited to, monitoring alarms and making or arranging for periodic contact in person and/or by telephone.

- Mobility services in and out of the home, including but not limited to, escort and driving.

In addition, there are important ancillary services which should be incorporated into a complete service system. These include durable medical devices such as wheelchairs and crutches, medical supplies, prescription drugs, home modification, and technology related services. Respite services are also a necessary support for many families of persons with disabilities.

The supportive services most utilized by persons with moderate to severe TBI are:

- Personal assistance services.

- Homemaker/chore support.

- Home health services.

- Respite services.

- Housing.

- Resource coordination (also known as "case management").

- Transportation.

- Advocacy.

Each support must be individualized and flexible if it is to work for the person with a disability. It is especially important to have supports designed specifically for each person with TBI, as cognitive factors vary from individual to individual. Compensatory strategies and community supports should address the uniqueness of the individual's particular needs, and certainly these needs may change over time. Backup supports and plans are also very important, and these should utilize natural support systems as much as possible.

Barriers, of course, impede the delivery and utilization of the community living supports needed by persons with disabilities, especially those with traumatic brain injury. Among the most obvious barriers are:

- Lack of funding - most persons with TBI and their families are often not familiar with funding sources other than those provided by their insurance policies. A resource/case manager familiar with various funding sources (SSI, SSDI, Medicaid waivers, state trust funds) can assist the family in accessing community supports.

- Attitudinal barrier - it is a widely held opinion that persons with disabilities cannot/should not live independently. A "safe environment" usually means a more restrictive lifestyle than the individual needs or chooses.

- Lack of affordable community-based living supports for persons with severe disabilities - the cost of placing persons in nursing homes and long-term care facilities is often less than community-based living. State Medicaid programs often will provide institutionalized care as opposed to community supports for this reason.

What is needed in the housing and support approach is a way of thinking focused on people's needs and including choices in housing, home locations and living arrangements. The need for individualized and flexible supports for community living should be based on, and driven by, consumer directive as much as possible.

The barriers and strategies noted below are illustrative, not exhaustive. It is recommended that this list be used by groups, agencies and policy makers to begin evaluating the local community services provided to persons with TBI.

- **Barrier:** Legislation, regulations, and policies may prohibit community living support services from being provided in people's own homes. This leads to institutionalization in nursing homes, homelessness, and/or undue burden on family.
  Strategies: Changes in state nursing practice acts; modification of Medicaid waiver to allow supports in people's own homes.

- **Barrier:** The types and amounts of available community living support services may be limited.
  Strategies: Expansion of personal assistance services to people with moderate to severe TBI; funding for emergency needs; broader and more flexible definitions of service categories in Medicaid waivers.

- **Barrier:** Services are designed around supervision needs of persons with moderate and severe TBI.
  Strategies: Development of individualized and flexible community living support strategies, including use of natural support systems.

- **Barrier:** The current design of case management services to persons with TBI does not adequately address a community-based vs. medical model.
  Strategies: Reconceptualization of the role of "service coordinator", "resource manager". An emphasis on community-based services with the consumer/family having a major role in designing plans and choosing services.

- **Barrier:** Lack of choice and self-determination on supports.
  Strategies: Consumer-directed supports whenever possible: strategies for promoting choice and decision making. Families play an active part as well, especially for those with survivors who are severely cognitively impaired.

- **Barrier:** Deficit-based assessment and program planning.
  Strategy: Individual community assessments and services planning.

- **Barrier:** Social isolation of persons with moderate and severe TBI.
  Strategies: Community participation strategies; housing which encourages community inclusion (example: apartment living with shared personal attendant services and readily available transportation).

- **Barrier:** Lack of funding for community living support services.
  Strategies: Cross-disability strategies for increasing funding and creating fiscal incentives for integration (advocates and survivors could join already existing disability coalitions or form new ones); advocate for state Medicaid waivers for community supported living arrangements.

- **Barrier:** Lack of emergency responsiveness.
  Strategies: Individual support plans, including provisions for backup support; home monitor systems hooked up to 24 hour emergency monitoring;

- **Barrier:** Attitudinal barriers against persons with traumatic brain injury.
  Strategies: Community and professional education regarding TBI; demonstrations of support services for people with severe disabilites (including TBI) in the community.

- **Barrier:** Lack of trained personnel (e.g. medical, health care, independent living) and community resources (e.g. supported employment services, peer support counseling).
  Strategies: Community-wide strategies for improving information base of key persons (medical, vocational, independent living personnel /agencies); promotion of best practice programs regarding community based services to persons with TBI.

- **Barrier:** Insufficient opportunities to participate fully in community of choice due to disability related issues (cognitive, behavioral, physical).
  Strategies: Personal assistance services, cognitive/behavioral therapy intervention as needed, peer support groups, Independent Living Center could have community skills training.

Funding Community Living Services: Medicaid Waiver: Section 1930

by

Linda J. Courtney, LMSW-ACP

Due to the growing number of persons with disabilities who wanted to live in the community of their choice, a movement to access community-supported living arrangements was initiated in the 1980's. Persons with disabilities and their advocates approached their legislators (state and federal) with a plan to use the Medicaid funds available for nursing home placement to pay for Community-Supported Living Arrangements (CSLA) services.

In late 1990, Congress enacted a new program in Medicaid that allows states to be reimbursed for providing CSLA services to person with developmental disabilities. This program is called Section 1930 of Title XIX of the Social Security Act. Section 1930, or CSLA, is the first Medicaid option to support the concept of providing services to persons with disabilities in their own homes (or community of choice) in order to maintain or enhance independence, productivity and community integration.

The program was initially limited to eight states, with a "cap" or limit on the amount of funds available for fiscal years 1991 through 1995. Twenty-seven individual states petitioned to the Health Care Financing Administration (HCFA) for the "Medicaid Waiver". A state plan for how the Medicaid funds would be used in community services instead of nursing home care was required. The eight states initially chosen were: California, Colorado, Florida, Illinois, Maryland, Michigan, Rhode Island, and Wisconsin. Nineteen states which applied for use of the funds were unable to cover CSLA services through their state Medicaid plans.

HCFA published interim final rules specifying the minimum protection requirements that must be met in order for a state to receive CLSA reimbursement. These include:

- Ensuring that individuals are protected from neglect, abuse, and financial exploitation.
- Ensuring that providers do not have histories of child or "client" abuse, neglect, or mistreatment or felonious harm to another person.
- Ensuring that providers are not unjustly enriched as a result of abusive financial arrangements.
- Ensuring that providers are prohibited from being named beneficiaries of life insurance policies on behalf of the individual.

Final regulations were published on October 1, 1992. There are also federal regulations regarding the states' extensive quality assurance role which are available.

The current status of Medicaid Waiver 1930 is one of hope. Not every person with a disability who is covered by the CSLA waiver can receive services, as only a designated number of "slots" are available and there are long waiting lists to receive community based services.

Persons with traumatic brain injury who sustained their injury prior to age 22 can benefit from this program. The CSLA waiver can assist in preventing institutionalization of young persons with TBI because they may have no other living options. The waiver also can provide respite care for parents and spouses of persons with TBI so that living in the community of choice is possible. Case management services paid for under the CSLA waiver can also assist the person with TBI in accessing and maintaining such resources as housing, vocational/educational services, and medical care. The following is a list of services a state Medicaid CSLA program may choose to provide. All of these services are not necessarily available in all states - an individual state plan can select those services they wish to provide their residents.

Medicaid Waiver - Section 1930

Services Proposed by States Applying for Section 1930 Medicaid "Community Supported Living Arrangements"

Case Management
Personal Assistance Services
Transportation
Assistive Technology/Adaptive Equipment
Environmental Modifications
Companion Services
Homemaker Services
Habilitation/Training Services
PT/OT/Speech Therapy
Behavior Management
Community Living Skills Training
Screening Assessment
Psychological Services
Support Services to Aid Participation in Community
Self-Advocacy Training
Independent Living Training

Supportive Living Consultation
Community Participation Services
Services for Retirees
Respite Care
Best Practices Training Services (support/self-actualization)
Supported Independence Living Coaching
Communication Aids
Counseling
Planning Group Activities
Service Brokerage
Community Resource Identification
Resource Development
Estate Planning
Housing Brokerage/Roommate Matching Services
Home Delivered Meals
Interpreter Services
Legal Services
Social Work Services
Nursing Services
Family Support Services
Communication Aids.

Note that the Medicaid 1930 waiver available in each state will be different and will reflect the needs and resources of that entity. Coalitions of persons with disabilities and their advocates can approach their state government with recommendations concerning which services they feel are most needed as community living supports.

Section E

Housing for Persons with Disabilities: Funding and Legal Issues

Housing for Persons with Disabilities: Funding and Legal Issues

Goal

Persons with traumatic brain injury and their families are often asked what community supports they need. An obvious, but often unattainable, support is housing. The need for affordable, accessible housing is becoming urgent as the return of persons with TBI to the communities of their choice increases. Housing for many persons with moderate to severe TBI has been long-term nursing home placement, or living with parents who are often not financially or physically prepared to care for an adult with a disability. Of major concern in accessing housing for persons with disabilities are: a) funding and b) accessibility. The information provided is intended to assist persons with TBI, their families and advocates in becoming more knowledgeable about resources available to persons with disabilities in the area of community-based housing.

Objectives

1. To identify types of housing options and established housing programs that are available to individuals, groups and agencies for construction, rehabilitation or maintenance of housing for persons with disabilities.

2. To identify funding resources and strategies for obtaining housing for persons with disabilities.

3. To identify legal rights of people with disabilities in obtaining and retaining housing.

Selected Resources for Housing for Persons with Disabilities: Funding and Legal Issues

Articles and Books

The First Five Years: 1980-1985. St. Paul, MN: Accessible Space, Inc.; 1986.

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Condeluci A, Gretz-Lasky S. Social Role Valorization: A Model for Community Reentry. Journal of Head Trauma Rehabilitation. 1987; 2(1):49-56.

Kreutzer J, Wehman P, eds. Community Integration Following Traumatic Brain Injury. Baltimore, MD: Paul H. Brookes; 1990.

Racino J, Walker P, O'Connor S, and Taylor S, eds. Housing, Support, and Community: Choices and Strategies for Adults With Disabilities. Baltimore MD: Paul H. Brookes; 1993.

Rosenthal M, Bond M, Griffith E, Miller J, eds. Rehabilitation of the Adult and Child With Traumatic Brain Injury. 2nd ed. Philadelphia, PA: F.A. Davis; 1990.

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VanderSchaaf S. An Operational Model of Lifelong Living. Journal of Head Trauma Rehabilitation. 1990; 5:40-46.

Housing for Persons with Traumatic Brain Injury

by

Gary Kather, MPA, and Terry Pettruci-Coley, MA, CCC-SLP

The acute medical intervention and rehabilitation of persons with traumatic brain injury (TBI) has improved from a medical and cognitive perspective in the past several years. These advancements are allowing persons who received moderate to severe injuries to live much longer lifespans. The dilemma often faced by many survivors and their families is the lack of affordable and accessible housing in the community of choice. Due to the lack of community housing with the necessary supports needed by many persons with TBI, a large number of survivors have had to live in nursing homes, adult foster care, or return to live with parents (or other family members) who are not prepared to resume caretaking, especially of an adult. Also, persons who have sustained injuries as children and have lived with parents all their lives may be facing a time when their parents will no longer be able to provide housing and needed supports. It has become imperative in the planning of supports for community integration of persons with TBI to look at long-term and permanent community housing options.

Types Of Housing

A variety of community-based housing options is now emerging for persons with disabilities. The options to nursing home placement or living in a parent's home with no support services are increasing, but it is important to know what the options are and how to access them. The following is a list of possible housing options available to persons with TBI:

- **Transitional living programs** - community-based residential programs where interdisciplinary therapies are provided. The goal is to increase independence and to move to a less restrictive environment. These are not permanent living situations, and length of stay is usually under two years.

- **Group homes** - long-term supported living environments housing eight or less residents. A hired staff manages the home and supervises the residents.

- **Supervised apartments** - a support agency leases several apartments in an apartment complex and has an on-site staff member available on an as-needed basis.

- **Supervised independent living facilities** - persons with disabilities reside in an apartment or group home with staff support from a rehabilitation facility available on an as-needed basis.

- **Congregate living** - a housing facility that is most often funded by a non-profit agency. Persons have their own rooms, but share activity rooms and dining areas.

- **Renting a residence -** (home or apartment) alone, or with one or more co-tenants. Support services such as personal attendant services are provided separately from housing and are not "program-based". This model is often called "supported living".

- **Home ownership** - persons with disabilities may purchase homes through various Housing and Urban Development (HUD) programs, may benefit from a "housing-in-trust" situation, or may participate in a housing cooperative where a group buys the property and the individual buys a share of the house or the building complex.

- **HUD funded permanent housing** - this is usually Section 8 housing where a person with a low income and disability status is provided either with a voucher or certificate to pay for housing, usually in designated apartment houses. This type of housing is managed by an agency (example: Volunteers of America) who manages the property but is not responsible for providing support services.

Funding Sources

Public Funding

The U.S. Department of Housing and Urban Development (HUD) has several programs to assist in providing affordable and accessible housing. These include:

- **"Supportive Housing for Persons with Disabilities", also known as Section 811 Housing** - This program provides capital advances to private, nonprofit organizations for the development of housing with supportive services for persons with disabilities. Project rental assistance funds are also provided so that the residents pay no more than 30% of their adjusted incomes for rent. Supportive services are essential to enable persons with disabilities to live independently in the community. Since HUD does not pay for supportive services, sponsors must provide commitments to HUD that necessary supportive services will be funded on a long-term basis to help assure that the housing will become a successful and viable addition to the community in which it is to be developed.

- **Section 8 Certificate and Voucher Programs** - This program provides persons with low incomes with a voucher or certificate to pay for housing in the community. There are limits on the amounts of monthly rent that landlords may charge rentors in this program. Individuals renting Section 8 housing must have very low income. This program is administered through local housing authorities and there is usually a long waiting list.

- **"Homeownership and Opportunity for People Everywhere" (HOPE) Program** - HOPE allows people to purchase public housing, multiple family homes and single family homes. Another HUD-sponsored program for low income housing is the HOME Program. These programs have very specific guidelines; call your local HUD office and request information concerning these programs.

- **State housing agencies** - They often have money available for the purchase and/or renovation of housing for the elderly and persons with disabilities. (Example: Texas Department of Housing and Community Affairs has a Housing Trust Fund which awards grants for housing needs of special populations). Individual states also administer the HUD HOME Programs, which are federally authorized and funded housing programs. Funds are available for development of affordable housing for persons and families of low and very low income. This program draws on the expertise of a wide variety of affordable housing advocates across states to create partnerships between the public and private sectors. HOME funding may be used to provide rental and home ownership housing through acquisition, rehabilitation, new construction (restricted to HUD-designated cities) and tenant-based rental assistance.

- **Farmers Home Administration (FmHA)** - This is a federal program administered under the U.S. Department of Agriculture. It provides loans in rural areas to finance homes and building sites. Rural areas include open country and places with population of 10,000 or less and, under certain conditions, towns and cities between 10,000 and 20,000 population. Home ownership loans may be used to buy, build, improve, repair, or rehabilitate rural homes and related facilities, and to provide adequate water and waste disposal systems. FmHA loans are offered to help families or persons with low and moderate income who are without decent, safe, and sanitary housing and are unable to obtain a loan from any other source. Applications are made at the Farmers Home Administration county office serving the area in which the house or farm service buildings will be located. For further information, contact the Farmers Administration, U.S. Department of Agriculture, Washington, DC 20250.

Other Funding Sources

- **Local banks** - Under the Community Reinvestment Act of 1978, banks were required by the federal government to "reinvest" profits back into their home communities. All banks have Community Re-Investment officers who can be contacted about housing loans (both for purchase and rehabilitation of existing buildings). Each branch of a bank has a specific area in which they are mandated to invest, so a bank located in the area of interest to the consumer should be approached.

- **Trust funds** - Trust funds offer opportunities to set aside money for housing which will not jeopardize a consumer's status with entitlement programs under the Social Security Administration (SSI and SSDI). The Supplemental Needs Trust should be investigated as a source of money to be used for housing.

- **Multi-family/individual consortium projects** - These projects allow parents (and/or consumers to combine money to fund housing and some support services. State agencies can pay for additional services (example: personal attendant services). This concept is relatively new and only a few states are using it at this time. The state of Ohio is currently a leader in developing this model.

- **Non-Profit Housing Corporations** - These corporations permit the joint operation of a housing development by those who live in it. All property is owned by a corporation. The corporation's "Articles of Incorporation and Bylaws" are specially designed so the corporation can be owned and operated by its members (stockholders). A member of a cooperative does not own his dwelling. He/she owns a membership certificate or stock in the corporation which carries with it the exclusive right to occupy a dwelling unit and to participate in the operation of the corporation directly as an elected board member or indirectly as a voter. Each state has its own regulations regarding non-profit housing corporations. Also, the co-op does not provide support services, thus separating housing from services.

- **Developmental Planning Councils** - These state councils can be a source of money for housing. These councils are appropriated money each year from the federal government to provide housing funds for persons with developmental disabilities. Most state guidelines specify that the disability must have occurred prior to the person's 22nd birthday, but some states have stricter criteria. Contact the Developmental Disability agency in your state for eligibility guidelines and information on housing funds. Also, ask if your state has the "Home of Your Own" program which offers support and technical assistance in home ownership to persons with developmental disabilities and their families. This assistance involves purchasing, or otherwise securing, economically and personally appropriate housing.

- **"Habitat for Humanity"** - This is a national foundation which works through communities to provide safe and affordable housing for the elderly, persons with disabilities, and persons with low incomes. Contact your nearest office for information about what is available for persons with disabilities.

- **Churches and philanthropic agencies** - They can be approached regarding housing and support services for persons with disabilities. Agencies such as Volunteers of America (VOA) are actively involved in communities throughout the United States, and have been very successful in writing grants and receiving federal and private money for the housing needs of the elderly and persons with disabilities. Catholic Charities is another organization which could be approached regarding housing.

Protection Under The Law

The Federal Fair Housing Amendments Act of 1988 prohibits all forms of discrimination in the sale or rental of a dwelling to the buyer or renter because of that person's disability (handicap). It applies to almost every kind of housing which does not fall within very limited statutory exemptions. The term "handicap" means a person who meets the following criteria:

- The person has a "physical or mental impairment which substantially limits one or more major life activities".
- The person has a record of such an impairment.
- The person is regarded as having such impairment.

Persons who are currently using illegal drugs are not covered. The law also does not protect someone who would be a direct threat to the health or safety of others or who would cause substantial damage to the property.

The Fair Housing Act, as amended, requires "reasonable accommodation in all rules, policies, practices or services, when such accommodation may be necessary to give a person with a disability an equal opportunity to use and enjoy a dwelling, including public and common use areas".

The Fair Housing Act and other housing related federal and state laws have detailed regulations and procedures. However, they are available from various sources and should be consulted to obtain or enjoy the use of a "dwelling" by people with traumatic brain injury.

The "Low Income Housing Preservation and Resident Homeownership Act of 1990" (LIHPRHA) provides "priority purchasers" with a 12-month exclusive negotiation period to present offers for prepayment eligible projects. Priority purchasers include eligible nonprofit organizations, public bodies and tenant associations. This is an excellent source of money for financing housing for persons with disabilities in their communities.

The Housing and Community Development Act of 1992 is administered by the Department of Housing and Urban Development. HUD requires each region to submit a five year plan for affordable housing. The Comprehensive Housing Affordability Strategy (CHAS) is a community plan which individual communities and municipalities submit to HUD outlining their plans for affordable housing. "Entitlement cities" of 50,000 or more can write their own CHAS. "Non-entitlement cities" of less than 50,000 must abide by the state HUD/CHAS plan.

Resources For Housing for Persons with Disabilities

Some key agencies providing information and services on housing for people with disabilities are:

- **State and local housing authorities**
  Services: Administer several federal and state housing programs for elderly, disabled and low-income citizens.

- **Protection and Advocacy systems in all states**
  Services: Information and referral as well as advocacy in fair housing issues for people with disabilities.

- **U.S. Department of Housing and Urban Development**
  Housing Discrimination Hotline
  (800) 669-9777
  TDD: (800) 927-9275
  Fair Housing Act Information Clearinghouse
  (800) 343-3442
  Services: Provides information and referral about virtually all aspects of fair housing and federally subsidized housing programs.

- **Housing for Elderly and Handicapped People Division**
  Department of Housing and Urban Development
  451 7th Street, SW, Room 6116
  Washington, DC 20410
  (202) 708-2866
  Services: Responds to inquiries and provides written information concerning the Section 811 program as well as other HUD programs that can be used by and for persons with disabilities.

- **State/Local Head Injury Foundation Chapters**
  Services: Provides information and referral on many community integration issues for persons with TBI. See pages A.3 - A.4 for telephone numbers.

- **Local Independent Living Centers**
  Services: Provide information and referral about community living resources for persons with disabilities. To locate the ILC closest to you call:
  Independent Living Research Utilization
  2323 South Shepherd, Suite 1000
  Houston, TX 77019
  (713) 520-0232

- **State Developmental Disability councils or agencies.**

Questions and Answers on Community Housing and Rent Subsidies

Reprinted with permission of The Center for Community Change through Housing and Support, Rent Subsidies - A Key to Community Housing. In Community. 1993; 3(1).

Q) What are three **barriers to community housing**?

A) 1. Lack of low income housing.

2. Discrimination.

3. Poverty of the disability group.

Q) What causes the **lack of low income housing**?

A) 1. Federal housing policies of the 1980's resulted in an 80% decline in production of low income housing units

2. Community opposition to low income housing development has become quite sophisticated (zoning laws, land use restrictions, and service requirements).

Q) What is the most common source of **income for persons with disabilities**?

A) Supplemental Security Income (SSI). Nationally, SSI income is only 24% of the national median income for one person households.

Q) What is "affordable housing" according to HUD?

A) Housing is defined as affordable if the person pays no more than 30% of his/her net income for rent and utilities. However, most "affordable housing" is targeted to help persons at 60%, 80% and over 115% of the median income, putting "affordable housing" well beyond the income of people with severe disabilities.

Q) Why are developers not interested in developing housing where a person on SSI pays only 30% of his/her income for rent?

A) It is difficult for the property owner to make enough rental income to pay the basic operating expenses (property management, taxes, repairs) plus the mortgage for the property.

Q) Are there other problems besides a shortage of housing?

A) Yes. The major problems in communities that don't have a shortage of housing is access to, or affordability of, existing housing units by persons with disabilities.

Q) What **long-term strategies** are being used by community service providers and advocates to address this housing problem?

A) 1. Expanding consumer employment.

2. Raising the federal SSI benefit.

3. Urging renewal of the federal government's funding of affordable housing.

Q) What is the **short term strategy** to address the problem?

A) A key strategy to promote access to housing is a rent subsidy that pays the difference between the portion that the person can afford (usually 30% of their income) and the fair market rent typical to their community.

Q) What **rent subsidy programs** are currently available?

A) 1. **Unit-based subsidies.**

2. **Portable or tenant-based subsidies.**

3. **Temporary subsidies**.

Q) What are **unit-based subsidies**?

A) Unit-based subsidies are attached to a specific apartment or unit of housing. One of the better known unit-based subsidy programs is in elderly and handicapped housing, managed by Public Housing Authorities.

Another frequently accessed housing resource is the HUD Section 811 (formerly 202) Program. This program develops group homes and apartments for persons with disabilities. In the past, 811/202 has been available only for development of segregated housing for persons with disabilities. Many states are now choosing not to use this funding in favor of the development of more integrated housing.

Low income housing also offer unit-based subsidies. However, they often are crime ridden and may be dangerous for persons with disabilities.

In some parts of the country, Stewart B. McKinney Homeless Assistance Act funds are available to develop permanent housing for persons with disabilities. These units have a subsidy, and are becoming a resource in the disability community.

HUD also provides construction and rehabilitation loans to private for-profit and private non-profit developers. These monies have funded unit-based subsidies in regular apartment complexes. These apartments are listed with the county, city or state Public Housing Authorities and the Farmers Home Administration (FmHA) also funds unit-based subsidies. The local Housing Authorities or local FmHA offices have information on the location of these programs/units and how to access them.

Many, but not all, states have special housing bond programs, trust funds and land trusts to finance housing development. The Housing Coordinator at the individual state's Department of Mental Health can be helpful in identifying the types of housing financing programs developed by the state.

Q) What are **tenant-based subsidies**?

A) The subsidy is attached to the tenant, rather than to the housing unit. The advantage of this is that the subsidy is "portable" and can be used in the general rental market.

HUD Section 8 Existing Program vouchers and certificates are the most common tenant-based subsidies. The **Section 8 certificate** pays the difference between 30% of the client income and the fair market rent rate for the unit. A Section 8 certificate can be carried within each state. **Section 8 vouchers** give the person a certain amount to spend for rent, and unlike a Section 8 certificate, a person with a voucher may pay more than 30% of his/her income for the balance of the rent. There is a great demand for Section 8 certificates, and waiting time may be years in some communities.

Some states have established their own tenant-based housing subsidy programs. Example: Massachusetts and New Jersey. Increasingly, states are creating their own temporary rent subsidy programs to help people afford housing while they are waiting for Section 8 and other assistance.

Q) What are **temporary rent subsidies**?

A) Due to long waiting lists for Section 8 certificates and vouchers, many Departments of Mental Health and some local mental health agencies have developed creative solutions to this dilemma by establishing temporary rent subsidy programs.

These programs provide a rent subsidy to the person until a Section 8 certificate is available. The subsidies can be used for regular housing and other housing-related expenses such as security deposits, moving expenses and rent payments while a person is hospitalized.

Q) What are some examples of **state supported rent subsidy** models?

A)

1. **Ohio Housing Assistance Program (HAP)** - administered through the local mental health boards in Ohio. It is funded from state general revenue funds and the mental health portion of the discretionary federal block grants. It can be used for tenant-based or project-based subsidies, and used for start-up costs such as security deposits, moving expenses, household furnishings.The subsidy is short-term, not to exceed two years, and is often used to subsidize consumer housing while they are on the Section 8 certificate waiting list.

2. **Vermont Housing Contingency Fund (VHCF)** - administered through Vermont's community mental health centers and is funded through the mental health portion of state general funds. Subsidies are tenant-based and may be used for start-up costs, partial rent payments while the client is on the Section 8 waiting lists, and partial or full rent payment for up to 60 days if a client is in the hospital.Generally this program pays no more than $125 towards housing costs per month. Recipients must be on the Section 8 waiting list and have priority status, must have a psychiatric disability, and must participate in housing planning with community mental health programs.

3. **Minnesota Rental Assistance Demonstration (MRAD)** - administered through Minnesota Housing Finance Agency. Funds are allocated from the Department of Health and Human Services general fund. MRAD requires the development of partnerships between local housing and social service agencies, in which they agree to work together and to share administrative responsibilities. Recipients are not required to obtain case management of mental health services in order to receive rental assistance.The program is tenant-based and has a subsidy of $150 per household for up to two years. **Eligibility requirements:** a person's income cannot exceed 30% of the area median

income, the individual is on the Section 8 waiting list, and he/she has a psychiatric disability. Subsidy can be used toward start-up costs, moving, furniture and can also pay the rent while an individual is hospitalized. This is one of six housing subsidy programs designed to serve adults with psychiatric disabilities in Minnesota.

4. **Wisconsin Housing Cost Reduction Iniative (HCRI)** - a generic housing program available to people on low incomes. Funds can be used for security deposits, rent payments under certain conditions, and a variety of costs associated with home purchase.

5. **Other States** - Tennessee and New York case management programs have a flexible pool of funds that is available to the case managers to pay for services that the consumer needs to succeed in community living, including a temporary rent subsidy. Texas Department of Mental Health and Mental Retardation has funded several supported housing demonstrations and development projects which have a funding allocation for temporary rent subsidies for the consumers who are served by the supported housing program.

Information and Resources for Supported Housing

Atlantis Community, Inc.
12 Broadway
Denver, Colorado 80203
(303) 733-9324

Center for Accessible Housing
School of Design
North Carolina State University
Box 8613
Raleigh, NC 27695-8613
TDD: (919) 515-3082

Center for Community Change through Housing and Support
Institute for Program Development
Trinity College of Vermont
208 Colchester Avenue
Burlington, VT 05401
(802) 658-0000

Center for Community Change
1000 Wisconsin Avenue, NW
Washington, DC 20007
(202) 342-0519

Independent Living Research Utilization
2323 South Shepherd, Suite 1000
Houston, TX 77019
(713) 520-0232

National Low Income Housing Information Service
1012 14th Street, NW
Washington, DC 20005
(202) 662-1530

Section F

Social Security Administratrion Programs for Persons with Traumatic Brain Injury

Social Security Administration Programs for Persons with Traumatic Brain Injury

Goal

The section will provide an overview of the Social Security Administration programs pertaining to persons with disabilities (specifically traumatic brain injury), and will increase consumer/professional awareness regarding how to access benefits from SSI/SSDI programs.

Objectives

1. To provide persons with disabilities and their advocates with the guidelines and eligibility requirements for the Supplemental Security Income (SSI) and the Social Security Disability Insurance (SSDI) programs.

2. To provide information on the Social Security Administration appeals process.

3. To provide an overview of the Social Security Administration Work Incentive Programs.

Selected Resources for Social Security Administration Programs for Persons with Traumatic Brain Injury

Articles and Books

Center for Independent Living of North Florida, Inc. Access Newsletters 1991 & 1992: Work Incentives, Parts 1-5. Tallahassee, FL.

Smith DM. Disability Workbook for Social Security Applicants. Arnold, MD: Physicians' Disability Services, Inc.; 1990.

Social Security Administration pamphlets: Disability, Your Social Security Rights and Responsibilities: Disability Benefits, When and How to Contact Social Security, Red Book on Work Incentives. Washington, DC: U.S. Department of Health and Human Services.

SSI/SSDI Eligibility for Persons with TBI
SSI/SSDI Work Incentives

by

Linda J. Courtney, LMSW-ACP

Supplemental Security Income (SSI) Basic Eligibility Requirements (1994)

Aged
- 65 or over.

or

Blind
- 20/200 Vision.

or

Disabled
- Illness/disability will last at least 12 months or result in death, and person cannot perform any substantial gainful activity during that time.

Income
- For one person must be:
  Below $466 with unearned income per month
  Below $977 with earned income per month
  Resources not to exceed $2000.
- For a couple must be:
  Below $689 with unearned income per month
  Below $1423 with earned income per month
  Resources not to exceed $3000.
- For a family the amount of allowable income and resources is dependent upon family size and composition.
- $1500 per person allowed for burial.

- U.S. Residence.
- Citizen or lawfully admitted immigrant.
- No waiting period for benefits to begin once eligibility is established.
- No work quarter requirements.
- Medicaid coverage is automatic in most, but not all, states.
- If approved, payment is made retroactive to date of application or to date of established onset of disability, whichever is later.
- Disability evaluation process generally takes approximately 90 days from application date.

Policies and Procedures are subject to change.
Call (800) 772-1213 for more information.

Social Security Disability Income (SSDI) Basic Eligibility Requirements (1994)

- Illness/disability to last 1 year or longer and be totally disabling.
- Must have worked and earned sufficient quarterly credits.

Age when Disabled	Credits Needed
Before age 24	6
Ages 24 through 30	13 (Average)
Ages 31 through 42	20
Age 50	28
Age 58	36
Age 62 or older	40

-or-

- Be a disabled widow or widower of a worker who was covered by Social Security at their death.

-or-

- Be a dependent of someone who is disabled.
- If approved, SSDI benefits will not begin **until the 6th full month of a disability**. This "waiting period" begins with the first full month after the onset of the disability.
- Amount of monthly disability benefits (SSDI) is based on the lifetime average earnings covered by Social Security.
- Medicare coverage begins after being on disability benefits (SSDI) two years.

Policies and Procedures are subject to change.
Call (800) 772-1213 for more information.

SSA Disability Determination Guidelines for Traumatic Brain Injury (1994 Guidelines)

The Social Security Administration (SSA) has guidelines for different disabilities. This information is compiled in Disability Evaluation Under Social Security, Parts A and B of the medical criteria (Listing of Impairments). To evaluate Traumatic Brain Injury as a disability, it is important to examine both the cognitive and physical status of the applicant.

Cognitive and neurobehavioral disabilities experienced by persons with traumatic brain injury should be evaluated according to the **"Mental Disorders: Organic Mental Disorders (12.02)"** category, found in the SSA Listing of Impairments.

Medical evidence will be needed and each of the doctors, hospitals, rehabilitation centers and other persons or facilities who have information regarding the applicant's condition (both physical and cognitive) should be contacted.

Medical evidence is defined as:

1. **Clinical signs** assessed by a physician, psychologist and/or neuropsychologist - these may include specific problems with memory, orientation, problem solving, and emotional difficulties as well as physical problems.

2. **Symptoms** which are complaints presented by the individual (example: "I have a hard time remembering details.").

3. Laboratory and/or psychological/neuropsychological test findings.

Functional Evaluation

Four areas of an applicant's life are considered when assessing mental disorder disabilities:

1. **Activities of Daily Living** - cleaning, shopping, cooking, taking public transportation, paying bills, maintaining a residence, personal care grooming, using telephones, post office, etc.

2. **Social Functioning** - a person's ability to interact appropriately and communicate with other individuals. Impaired social functioning can be documented by history of fighting, arrests, evictions, firings, fear of strangers, social isolation, etc.

3. **Concentration, Persistence and Pace** - the ability to sustain focused attention long enough to permit the timely completion of tasks commonly found in work settings. Neuropsycological evaluations and work evaluations can measure these.

4. **Deterioration or Decompensation in Work or Work-like Settings** - repeated failure to adapt to stressful situations which cause the person either to withdraw from that situation or to experience increased signs and symptoms with an accompanying difficulty in maintaining activities of daily living, social functioning, and concentration, persistence and pace.

A **marked** limitation in the above areas (one or more) is needed to prove disability, and must be serious enough to interfere with the applicant's ability to function **independently, appropriately and effectively**.

Also, it is important for the Social Security evaluators to know:

1. The ability of the person to function outside of a highly structured and controlled environment.

2. The effect(s) of medication on the person's signs, symptoms and ability to function.

3. The effects of treatment in relation to achieving an adequate level of adaptation required in the work place.

Documentation of these functional limitations can be given by:

1. Reports from individual providers such as physicians and psychologists.

2. Facilities such as hospitals and clinics.

3. Rehabilitation programs such as outpatient training programs for persons with traumatic brain injury.

4. Family members and friends.

5. School personnel such as teachers, school psychologists, social workers.

6. Actual observations by Social Security interviewers, state agency personnel (example: Texas Rehabilitation Commission vocational counselor), and information furnished by public welfare agencies or other reliable objective sources.

In addition to evaluating for Organic Mental Disorders, the individual's physical condition should also be assessed. In the SSA Listing of Impairments, the listing of **Neurological Impairments: Cerebral Trauma** (11.18) outlines specific criteria such as:

1. **Epilepsy/seizures** - if the individual experiences seizures in spite of medical treatment for at least three months (grand mal more than once a month or petit mal, psychomotor or focal more than once a week), he/she should be eligible for disability.

2. **Speech** - if the individual has sensory or motor aphasia resulting in ineffective speech or communication as a result of brain trauma, he/she should be eligible for disability.

3. **Disorganization of motor function** - persistent disorganization of motor function in two extremities (both legs, both arms, or one leg and one arm) resulting in sustained disturbance of gross and dexterous movements **OR** disturbance in gait and station (balance) should result in approval for disability.

This disorganization can be in the form of paresis or paralysis, tremor or other involuntary movements, ataxia, and sensory disturbances.

Documentation of the limitations must be from a physician or inpatient facility with a physician overseeing the treatment program, and must include the physician's "signs" (loss of sensation, loss of reflex, muscle atrophy, etc.) to support limitations.

Policies and Procedures are subject to change.
Call (800) 772-1213 for more information.

Region VI State Disability Determination Offices

Arkansas
Disability Determination for SSA
701 Pulaski Street
Little Rock, AR 72201
(501) 682-3030

Louisiana
Disability Determinations
P.O. Box 96074, Audobon Station
Baton Rouge, LA 70896
(504) 925-3533

Disability Determinations
P.O. Box 5916
Metairie, LA 70009
(504) 838-5000

Disability Determinations
P.O. Box 4446, Centenary Station
Shreveport, LA 71134
(318) 869-3441

New Mexico
Disability Determination Unit
P.O. Box 4588
Albuquerque, NM 87196
(505) 292-6711

Oklahoma
Disability Determination Services
P.O. Box 25352
Oklahoma City, OK 73125
(405) 840-7770

Texas
Division of Disability Determinations
P.O. Box 2913
Austin, TX 78769
(512) 445-8000

To contact the State Disability Determination Office in your area, call (800) 772-1213.

Social Security Administration Appeals Process

It is very important to file for SSI/SSDI benefits as soon as possible after a moderate to severe traumatic brain injury. Do not delay filing for benefits just because you do not have all the information you need. The date of the **initial application** is very important; retroactive benefits can be paid to a successful applicant during the 12 months prior to the date of the SSDI application and for all benefits payable after the date of the application up to the date of the award.

Only 37% of applicants win their first decision. **Always appeal** if turned down at the initial application.

There are four appeal steps:

1. **Reconsideration** - You may request a review of your case if you disagree with the first decision. Then, a person other than the one who made the first decision will review the case again. Most applicants will again be denied benefits.

2. **Hearing** - You may request a hearing before an Administrative Law Judge if you disagree with the Reconsideration decision. It is a good idea to have representation by an attorney or other professional qualified to present your case. Consider contacting your local Legal Aid office regarding legal representation. Awards are won by approximately 60% of applicants who appeal at this level.

3. **Appeals Council Review** - You may request the Appeals Council to review your case if you disagree with the Administrative Law Judge's action. This Council will either decide your case or return it to the Administrative Law Judge for further action.

4. **Federal Court** - You may request an appeal through the U.S. Court system, starting with the U.S. District Court, if you disagree with the Appeals Council's decision or denial of your request for review. Such an appeal is often necessary. Always have legal representation at this stage of appeal.

Overview of Work Incentives for SSI/SSDI Recipients

If a person with a disability receives SSI or SSDI there are special benefits he/she can get to help make the transition to full-time self-supporting work.

These are called "Work Incentives" and they do four things:

1. Provide the working person who has a disabilty with the security of knowing that his/her disability benefits will not be cut off, in case their new employment should not work out.
2. Provide for certain expenses associated with returning to work.
3. Provide enough income to live independently until the person's salary is high enough to cover living expenses.
4. Provide permanent subsidies for those who need them.

The Work Incentives available to people who receive either SSI or SSDI, or both, are:

1. Impairment-Related Work Expenses (IRWE).
2. Employee Subsidies.
3. Continued Payment under a Vocational Rehabilitation Program (known as Section 301).

The Work Incentives available to people who receive SSDI are:

1. Impairment-Related Work Expenses (IRWE).
2. Trial Work Period (TWP).
3. Extended Period of Eligibility (EPE).
4. Medicare Buy-In.

The Work Incentives available to people who receive SSI are:

1. Earned Income Exclusion.
2. Impairment-Related Work Expenses (IRWE).

3. Blind Work Expenses.

4. Plan for Achieving Self-Support (PASS).

5. Property Essential to Self-Support (PESS).

6. Section 1619 Work Incentives.

7. Student Earned Income Exclusion.

Eligibility Guidelines

All work incentives have eligibility periods and income cut-offs. The eligibility periods are those times, usually shortly before or immediately after returning to work, when an SSI/SSDI recipient **must** apply for work incentives. If a request is not filed in time and an eligibility period is missed, work incentive benefits will not be assigned.

Here are the steps a person with a disability should take as he/she begins to search for a job:

1. Write to the Social Security Administration Region VI Office and request a copy of the **Red Book on Work Incentives**, also known as "SSA Publication No. 64-030". The address is:

Regional Commissioner, SSA
Attn: Disability Programs Branch
1200 Main Tower Building
Room 1440
Dallas, TX 75202

For the Regional office nearest you call (800) 772-1213.

2. Keep accurate and detailed records of all expenses related to work which are not paid for by another source (vocational rehabilitation, private insurance, public schools).

Policies and Procedures are subject to change.
Call (800) 772-1213 for more information.

Supplemental Security Income (SSI) Work Incentives (1994 Guidelines)

Supplemental Security Income (SSI) is the benefit paid to people who do not have a substantial work history before they become disabled, such as persons who are disabled from birth. People who are eligible for SSI have little or no income and few other resources.

The following are the Work Incentives that apply to SSI:

Earned Income Exclusion

If an SSI recipient has an unearned income such as benefits from a trust, the Social Security Administration (SSA) subtracts all but $20 of that amount from the SSI check. Earned income, such as wages or a salary, is treated differently. An SSI recipient can earn up to $500/month and less than half of that amount is counted as income. The first $20 of the recipient's earned income are excluded under the "General Income Exclusion" and the next $65 are excluded under the "Earned Income Exclusion". Half of the remainder of the recipient's earned income is then also excluded. The SSI benefit is reduced by the amount of 1/2 of the remainder of the recipient's earned income.

"Income Exclusion" is the income SSA does NOT count when computing how much a recipient is entitled to in benefits, NOT the amount of benefits he/she will receive.

The SSI recipient can earn up to $500/month and still receive some SSI benefits. This work incentive benefit will run for the lifetime of the SSI recipient, or until his/her earned income rises above $500. For blind persons, the income limit, or "substantial gainful activity," is $810.

A separate "Student Earned Income Exclusion" also exists. An SSI recipient under 22 years of age attending a college/university for at least 8 hours a week, or a high school or work training program for at least 12 hours a week, may earn $400/month, or up to $1,620/year.

This income is excluded before the standard earned income exclusion is figured. The student remains eligible for the Student Earned Income Exclusion if he/she is participating in homebound instruction or cannot attend school/training for the full number of hours required because of health problems; however, the required time in school rises to 15 hours/week if shop practice is included in the school or training program.

Records to keep:
Pay stubs and a copy of all correspondence with SSA.

Blind Work Expenses

A blind person who receives SSI may exclude from his/her benefits **all** of the expenses he or she must cover in order to work. These benefits include: guide dog expenses, transportation to and from work, Federal, State and local income taxes, FICA, attendant care, visual and sensory aids, translation of materials into braille or onto tape, professional association fees, union dues, adaptive equipment, safety gear, etc. The expenses do NOT have to be related to blindness.

The Blind Work Expenses work incentives are deducted from the Earned Income Exclusion, then the Earned Income Exclusion is computed.

Records to keep:

- Dated receipts of all work-related expenses kept in chronological order.
- An itemized list with totals for each month.
- Complete records of all correspondence with SSA.

Plans For Achieving Self-Support (PASS)

An SSI recipient is not allowed to own more than $2,000 in resources. There are exceptions, such as a car or expensive wheelchair, but in general no more than $2,000 in savings or property can be accumulated without affecting the SSI check amount.

However, with PASS an SSI recipient can accumulate savings or property for up to four years, if the goal of the PASS is to return to work. A PASS plan may also be filed when applying for SSI, to allow the recipient to keep property or savings that he/she would otherwise have to sell or use up before qualifying for SSI.

A PASS consists of a written plan listing the steps a consumer plans to take to prepare for work, the amount of money needed, the expenses the consumer will have to cover and their exact amounts, the source(s) of the income to be used for the PASS and a timetable that explains when work will start. A PASS plan must be approved by the consumer's local SSA office and is subject to a periodic review by the local SSA office.

A PASS plan can be used to shelter income a consumer receives from their family, if they set it aside for training or other job-related expenses. A PASS plan can be used to allow the consumer to keep their savings after they become disabled and apply for SSI. Any income or property the recipient can use or save for the purpose of returning to work can be set aside under PASS.

The SSA encourages the SSI recipient to receive outside help when he/she prepares the PASS, because they may be required to document that the capacity for performing the work the consumer plans to seek, and that the plan to start work, are reasonable.

There are no specific restrictions on what the PASS money can be used for, as long as it is spent on expenses directly related to work. These include tools, adaptive equipment, attendant care, modified vehicles, training, school, and special medical expenses.

SSI benefits can be increased through PASS if a plan is submitted calling for a small amount of money per month to be added to the SSI check. Large, expensive items are rarely approved, but SSA will add $100 or so for a specific, ongoing purpose.

Records to keep:

- The written PASS plan.
- Itemized month-by-month records, with the original receipts of the income and/or property received or used under PASS.
- Itemized month-by-month records, with the original receipts, of all PASS expenses.
- A month-by-month narrative of progress toward completing the PASS and a complete record of correspondence with the SSA.

Property Essential To Self-Support (PESS)

PESS allows an SSI recipient to keep property he/she owns (or may acquire, such as through an inheritance) which is essential to a job or business in which he/she earns a living. All tangible goods, like tools or vehicles, are covered completely. Land on which a recipient owns a business or raises crops for sale or his/her own consumption is also covered completely. Up to $6,000 of equity value in a non-business property needed for self-support is also excluded, such as land on which food is grown for self/family consumption.

If an SSI recipient does not have a PESS, SSA will require him/her to sell all their property (land or other property) in excess of $2,000 and live on the proceeds until all that money is spent. After a recipient has only $2,000 in property, he/she may then be eligible for SSI.

Records to keep:

- An inventory of the property in PESS.
- A complete monthly chronological accounting with the original receipts of all the income and/or other benefits received from the property.
- A complete record of all correspondence with SSA.

Section 1619 (a): Special SSI Payments For People Who Work

Once an SSI recipient passes the Substantial Gainful Activity Level of $500 ($810 for blind persons) he/she may still receive SSI by excluding some work income. SSA will calculate the exclusion the same way the Earned Income Exclusion and Student Earned Income Exclusion are calculated. First, SSA will exclude the first $20 of income under the general exclusion, and the next $65 of income under the work exclusion. Next, SSA will exclude half of the rest of the earned income, up to $500. The total earned income that can be excluded under the Section 1619(a) is $385 (that is, $20 + $65 + 1/2 of $500). If the earned income falls less than $500 after the exclusion, the person can receive some SSI benefits.

Section 1619 (a) can be used in conjunction with PASS or with the Impairment- Related Work Expenses incentive. If monthly work-related expenses are covered by PASS or IRWE, they can be taken off the top and then apply all income exclusions. A separate file of records must be kept for each program.

Records to keep:
Pay stubs and copies of all correspondence with SSA.

Section 1619 (b): Continued Medicaid Eligibility

An SSI recipient may continue to receive Medicaid even if he/she no longer receives SSI, if their income is below a threshold. The threshold is: the amount of income which would cause the recipient to lose SSI benefits, plus the per person expenditure on Medicaid (determined by each state) minus the IREW/PASS/BWE income exclusion.

Records to keep:
Copies of all correspondence with SSA.

Impairment-Related Work Expenses (IRWE)

This work incentive enables the SSI recipient to start working at an entry level salary and continue to receive benefits in order to pay for personal care, durable and disposable medical supplies, vehicle modifications and transportation expenses, medical care and special adaptive devices which are used on the job.

The IRWE are calculated and then subtracted from earnings. Only earnings left over (after the IRWE are deducted) are used to determine whether the SSI recipient has reached the substantial gainful activity level.

The expenses that go into IRWE must meet three criteria:

1. The expense must be directly related to the impairment and general work-related expenses.

2. They must be strictly work-related and not general impairment-related expenses.

3. No third party, such as private insurance, Medicare, Medicaid, employer or Vocational Rehabilitation can pay the expenses. It must be paid for by the SSI recipient without reimbursement.

Records to keep:

- Receipts and canceled checks for every expense to be included in the IRWE.
- Chronological log listing all the expenses in the IRWE, with a brief narrative description of each.
- Medical documentation establishing the existence of disability(ies) and the need for the adaptive devices and related services needed to work.
- Complete copies of all correspondence with the SSA.

Subsidies Received On The Job

Subsidies are reasonable accommodations an employer makes to enable a worker with a disability to hold a job when that worker cannot perform the tasks in the same manner as an able bodied worker. Examples of subsidies would be: job coaches, fewer and simpler task assignments than an able bodied worker. SSA deducts the value of the subsidy from the earnings when they calculate whether the substantial gainful activity test has been met.

The Subsidy Work Incentive seems to be designed for use primarily in sheltered workshops, supported employment and similar programs.

Records to keep:

The employer should keep copies of all his/her correspondence on each SSI recipient's case with SSA.

Policies and Procedures are subject to change.
Call (800) 772-1213 for more information.

Social Security Disability Income (SSDI) Work Incentives (1994 Guidelines)

Social Security Disability Income (SSDI) is the benefit paid to persons with disabilities who have a substantial work history before they become disabled and lose their jobs. During a person's working years he/she pays special taxes (known as "FICA") which the employer matches. After a person becomes disabled, the Federal government then pays SSDI benefits.

SSDI benefits are based on:

1. Length of time worked.

2. The amount of money made.

The amount of SSDI benefits are calculated from earnings over the last 40 "quarters" (three month periods, or quarters of a year) of a person's working life. Unlike SSI, other income is irrelevant when SSDI benefits are calculated; as long as a the person is not working and earning money, other benefits can be collected as well. Many SSDI recipients have private pensions or other benefits they collect in addition to their SSDI benefits. Only certain Worker's Compensation and State/civil service benefits can be subtracted from SSDI benefits.

A non-blind SSDI recipient can earn up to $500 per month without losing any of his/her SSDI benefits; a blind SSDI recipient can earn up to $810 per month without losing benefits (1993 guidelines). Anything over $500 (or $810) a month is "**Substantial Gainful Employment**".

The following are Work Incentives that apply to SSDI:

Trial Work Period

An SSDI recipient may work for nine months and receive full SSDI benefits. If the recipient cannot continue working, for whatever reason, SSDI benefits continue without an interruption. If the work arrangement is a success, the recipient receives three (3) more months of cash payments after the Trial Work Period, and then SSDI payments are ended. Here are some facts about the Trial Work Period:

1. The Trial Work Period begins with the first month that more than $200 is earned.

2. After a recipient has worked nine months, the Social Security Field Office will review the case and determine if the person is earning at the Substantial Gainful Activity (SGA) level ($500/month or more).

3. If so, the SSDI recipient will receive three more months of benefits; if not, the person will receive the same benefits he/she had been receiving without change.

Although nine months of Trial Work Period is usually all that is allowed, they do not have to be nine continuous months. After sixty months (five years) of working, the recipient may be able to get another nine-month Trial Work Period, which he/she can use if he/she loses the job and returns to SSDI. A new nine-month Trial Work Period can be obtained if the person develops a new disability and becomes re-eligible for SSDI after having worked a while.

An SSDI recipient must notify his/her local Social Security Administration (SSA) office that they will be returning to work.

Records to keep:

- Copies of each paycheck.
- Copies of any papers related to dismissal if he/she loses their job.
- Copies of all correspondence with the SSA.

Extended Period Of Eligibility

This is another "buffer zone" work incentive. If an SSDI recipient loses a job for any reason during the first 36 months (three years) after returning to work, he/she can re-establish eligibility for SSDI without having to reapply for it. Checks can be resumed at once, without the five-month waiting time usually required by the SSDI rules.

The Extended Period of Eligibility begins the month after the Trial Work Period ends. If an SSDI recipient has to leave work for any reason (such as a temporary medical difficulty) and he/she does not earn enough in that month for Substantial Gainful Activity, SSDI benefits can be obtained for that month. The Extended Period of Eligibility doesn't re-start at that point; it continues on until the 36 month limit is up.

Records to keep:

- Copies of each paycheck.
- Copies of any letters of dismissal if a job is lost or the person must take a leave of absence.
- Copies of all correspondence with the Social Security Administration.

Medicare Coverage / Medicare Buy-In

If an SSDI recipient has Medicare, he/she can continue to receive it during the Extended Period of Eligibility. Medicare coverage will run for 39 months from the date the Extended Period of Eligibility begins.

The recipient should automatically receive the Continuation of Medicare Work Incentive if he/she has Medicare and receives a Trial Work Period and Extended Period of Eligibility.

Another SSDI work incentive is called " Medicare for People with Disabilities Who Work". Essentially, this benefit allows an SSDI recipient to "buy-into" Medicare by paying a monthly premium, just as if a person were purchasing health care insurance from a private insurance carrier. If an SSDI recipient chooses to take part in the "Medicare for People with Disabilities Who Work" incentive, his/her State Government will automatically pay the hospitalization (Medicare Part A) premium and the recipient pays the Premium Supplemental Medical Insurance (Medicare part B).

This work incentive can be received only if the recipient has had the "Continuation of Medicare Coverage" work incentive. The SSDI recipient must apply for "Medicare for People with Disabilities Who Work" incentive between January 1 and March 1 of the year in which his/her "Continuation of Medicare Coverage" incentive will run out.

The SSDI recipient buys Medicare coverage for the rest of his/her working life, until he/she retires and becomes eligible for Medicare as a retiree.

In addition to the work incentives designed especially for SSDI recipients, there are two work incentives designed for people who receive SSI, SSDI, or both. These are:

Impairment-Related Work Expenses (IRWE):

This work incentive enables the recipient to start working at an entry level salary and continue to receive SSI/SSDI benefits in order to pay for his/her personal care, durable and disposable medical supplies, vehicle modifications and transportation expenses, medical care and special adaptive devices he/she may use on the job.

The IRWEs are calculated and then subtracted from earnings. Only earnings left over after the IRWE are deducted are used to determine whether the substantial gainful activity level has been reached.

The expenses that go into IRWE must meet three criteria:

1. The expense must be directly related to the impairment and not general work-related expenses.

2. The expenses must be strictly work-related and not general impairment-related expenses.

3. No third party, such as private insurance, Medicare, Medicaid, employer or Vocational Rehabilitation can pay the expense. The recipient must pay it out of his/her own money without reimbursement.

Records to keep:

- Receipts and canceled checks for every expense included in the IRWE.
- A chronological log listing all the expenses included in the IRWE, with a brief narrative description of each expense.
- Medical documentation establishing the existence of the recipient's disability(ies) and the need for the adaptive devices and related services he/she needs to work.
- Complete copies of all correspondence with the Social Security Administration.

Subsidies Received On The Job

Subsidies are reasonable accommodations an employer makes to enable a worker with a disability to hold a job when that worker cannot perform the job in the same manner as an able bodied worker. Examples of subsidies would be: job coaches, fewer and simpler task assignments than an able bodied worker. SSA deducts the value of the subsidy from earnings when they calculate whether a recipient has met the Substantial Gainful Activity test.

The Subsidy Work Incentive seems to be designed for use primarily in sheltered workshops, supported employment and similar programs.

Records to keep:

The employer should keep copies of all his correspondence on each employee with SSA.

Policies and Procedures are subject to change.
Call (800) 772-1213 for more information.

Section G

State Vocational Rehabilitation Agiencies - Implications for Persons with TBI

State Vocational Rehabilitation Agencies - Implications for Persons with TBI

Goal

This section will provide a basic understanding of the services provided by state Vocational Rehabilitation Agencies. An overview of the Rehabilitation Act Amendments of 1992 will cover newly established guidelines for eligibility criteria. The variety of services and special programs for persons with traumatic brain injury (TBI) will be emphasized. This information is not meant to be state specific, but give information regarding federal mandates to the states, who then administer their own state agencies.

Objectives

1. To provide information regarding eligibility requirements, financial need considerations and general services provided by state Vocational Rehabilitation Agencies based on the Rehabilitation Acts Amendments of 1992 (P.L. 102-569).

2. To provide information on the rights of persons with disabilities under the state Vocational Rehabilitation programs, and advocacy services available within the state Vocational Rehabilitation programs.

3. To provide information regarding how the provisions of the Rehabilitation Act Amendments of 1992 can affect services to persons with TBI.

State Vocational Rehabilitation Agencies and the Rehabilitation Act Amendments of 1992: Implications for Persons with Traumatic Brain Injury

by

Terry Kennedy, MPA, CRC

On October 29, 1992, Congress passed the Rehabilitation Act Amendments of 1992 (P.L. 102-569). The measure passed both the Senate and House of Representatives without opposition and was signed into law by President George Bush.

This legislation directly affects the funding and operation of state Vocational Rehabilitation Agencies. In general, the amendments emphasize returning persons with severe disabilities to employment settings. For the purposes of Title VII of the Act, the definition of "individual with a severe disability" is:

> An individual with a severe physical or mental impairment whose ability to function independently in the family or community, or whose ability to obtain, maintain, or advance in employment is substantially limited, and for whom the delivery of independent living services will improve the ability to function, continue functioning, or move towards functioning independently in the family or community or to continue in employment, respectively.

Under the Rehabilitation Act Amendment, all programs, projects and activities receiving assistance under this act will be carried out in a manner consistent with the principles of:

- Respect for individual dignity, personal responsibility, self-determination, and pursuit of meaningful careers, based on informed choice.

- Respect for the privacy rights and equal access, including the use of accessible formats for the individuals.

- Inclusion, integration and full participation of the individuals.

- Support for the involvement of a parent, family member, legal guardian, advocate or an authorized representative if an individual with a disability requests, desires, or needs such support.

- Support for individual and systemic advocacy and community involvement.

All states must submit state plans to the Commissioner of the Rehabilitation Services Administration (RSA) which include, but are not limited to, a designation of a single state Vocational Rehabilitation Agency to administer or supervise the administration of the federal grant funds. A State Rehabilitation Advisory Council will also be established by each state, and membership will include a majority of individuals with disabilities.

Some changes were made in the wording and intent of the new law to involve consumers more in directing their rehabilitation program as clients of state Rehabilitation Agencies and to encourage employment. According to the 1992 amendments:

- Individuals with disabilities, including those with severe disabilities, are generally presumed to be capable of engaging in gainful employment in integrated settings. An integrated setting is one in which persons without disabilities are employed.

- Individuals must be active participants in their own rehabilitation programs. Participation includes making informed choices about vocational goals, objectives and services.

- State Vocational Rehabilitation counselors will generally be required to determine whether the client is eligible for vocational services within 60 days of application for services.

- When denying services, the state Rehabilitation Agency must have clear and convincing evidence that an individual is incapable of benefitting from services in terms of employment outcome. Furthermore,prior to closing an individual's case as "ineligible for reasons of being too severely disabled", a period of extended evaluation must be provided.

- Individual Written Rehabilitation Programs (IWRPs) must be jointly developed between the individual and counselor. The IWRP will describe services and service providers, and include a statement by the individual in his/her own words describing how he/she was informed about and involved in decisions concerning the rehabilitation plan.

- Title I of the Act provides for on-the-job training or other work-related personal assistance services necessary for individuals to secure and maintain employment. Transitional services are also included.

- Supported employment services for persons with the most severe disabilities will include placement in an integrated work setting for the maximum number of hours possible. Placement is based on the unique strengths, resources, interests, concerns and abilities of the individual.

- Title VII of the Act promotes increased funding to states for expanding independent living services. These services include independent living skills training, peer counseling, advocacy and information and referral services.

- Section 201 of the Act re-emphasizes full inclusion and integration into society, employment, and independent living, as well as economic and social self sufficiency, for all individuals with disabilities.

Implications For Individuals With Traumatic Brain Injury

Persons with traumatic brain injury, especially those experiencing moderate to severe injuries, have cause to celebrate the Rehabilitation Act Amendments of 1992. Statistically, the rate for employment post-trauma is quite low (30% nationwide).

The Rehabilitation Services Administration (RSA) has in the last decade begun to address the specific employment needs and supports of persons with TBI. In 1992 the RSA introduced new statistical codes to be used by state Vocational Rehabilitation Agencies in reporting data on individuals who have a disability resulting from TBI. The 700 series of disability codes (700-744) are important in that TBI is now considered a distinct disability group requiring its own service/ treatment practices.

The information provided by a comprehensive neuropsychological evaluation (performed by, or under the direction of a qualified neuropsychologist) can assist the state VR counselor in assessing current cognitive and behavioral status of persons with TBI. A neuropsychological evaluation can:

- Provide a diagnosis and information to assist in establishing that the individual sustained a brain injury and will need assistance from the state Vocational Rehabilitation Agency to gain or maintain employment.

- Define the degree of cognitive functioning of the person with TBI.

- Provide a baseline of cognitive functioning from which progress can be measured, and assist in identifying vocational rehabilitation services needed by the client.

It is important to remember that a person with TBI should not be deemed ineligible for state vocational rehabilitation services until a comprehensive neuropsychological evaluation and a functional assessment indicate that the applicant cannot be employed in any setting, including sheltered employment. The Amendments Act now states that the person with a disability, regardless of the severity, can achieve employment and other rehabilitation goals if the appropriate services and support are made available, unless the rehabilitation counselor can demonstrate by clear and convincing evidence that no employment outcome is possible.

For persons with severe disabilities as a result of traumatic brain injury, an extended evaluation period may be needed past the 60 day eligibility determination guidelines.

Persons with TBI now have the benefit of receiving job coaching, service coordination assistance, and other forms of long-term support in order to achieve employability and independent living. Reasonable accommodations in the workplace to assist the client in performing the essential functions of the job are also mandated through the Americans with Disabilities Act. "Reasonable Accommodation", according to Federal Regulations, is interpreted as "modifications or adjustment to the work environment or the manner or circumstances under the position held or desired is customarily performed, that enable a qualified individual with a disability to perform the essential functions of the position". For persons with TBI these accommodations may include:

- Job restructuring to reduce the number of tasks assigned at one time.
- The use of tape recorded and/or written instructions.
- Elimination (or minimizing) of visual and auditory distractions in the work area.
- The use of computers and/or other assistive technology.

Vocational Rehabilitation State Agencies

Alabama
Division of Rehabilitation and Crippled
Children Service
Department of Education
2129 East South Boulevard
P.O. Box 11586
Montgomery, AL 36111
(205) 281-8780

Alaska
Division of Vocational Rehabilitation
Department of Education
801 West 10th Street, Suite 200
Juneau, AK 99801
(907) 465-2814

American Samoa
Vocational Rehabilitation
American Samoa Government
P.O. Box 3492
Pago Pago, American Samoa 96799
(684) 633-1805

Arizona
Rehabilitation Services Bureau
Department of Economic Security
1789 West Jefferson, 2nd Floor, NW
Phoenix, AZ 85007
(602) 542-3332

Arkansas

Division of Rehabilitation Services
Department of Human Services
7th and Main Streets
300 Donaghey Plaza, North
P.O. Box 3781
Little Rock, AR 72203
(501) 682-6708

State Services for the Blind
Department of Human Services
411 Victory Street
P.O. Box 3237
Little Rock, AR 72203
(501) 324-9270

California

Department of Rehabilitation
Health and Welfare Agency
830 K Street Mall
Sacramento, CA 95814
(916) 445-3971

Colorado

Division of Rehabilitation
Department of Social Services
4th Floor, 1575 Sherman Street
Denver, CO 80203
(303) 866-5196

Connecticut

Bureau of Rehabilitation Services
Human Services
10 Griffin Road North
Windsor, CT 06195
(203) 298-2000

Board of Education and
Department of Services for the Blind
Department of Human Services
170 Ridge Road
Wethersfield, CT 06109
(203) 249-8525

Delaware

Division of Vocational Rehabilitation
Department of Labor
321 East 11th Street
Wilmington, DE 19801
(302) 577-2850

Division for the Visually Impaired
Health and Social Services
Biggs Building
1901 North DuPont Highway
New Castle, DE 19720
(302) 577-4731

District of Colombia

Vocational Rehabilitation Services
Administration
Department of Human Services
605 G Street, NW
Washington, DC 20001
(202) 727-3277

Federated States of America

P.O. Box 400
Moen, Truk State
Federated States of Micronesia, 96942
011 (691) 330-2320

Florida

Division of Vocational Rehabilitation
Dept. of Labor and Employment Security
1709-A Mahan Drive
Tallahassee, FL 32399
(904) 488-6210

Division of Blind Services
Department of Education
2540 Executive Center Circle, West
Tallahassee, FL 32301
(904) 488-1330

Georgia

Division of Rehabilitation Services
Department of Human Resources
878 Peachtree Street, NE, Room 706
Atlanta, GA 30309
(404) 894-6670

Guam

Department of Vocational Rehabilitation
122 Harmon Plaza, Room B201
Harmon Industrial Park, Guam 96911
(671) 646-9468

Hawaii

Vocational Rehabilitation and Services
for the Blind
Department of Human Services
1000 Bishop Street, Room 615
Honolulu, HI 96813
(808) 548-4769

Idaho

Division of Vocational Rehabilitation
State Board for Vocational Education
Boise, ID 83720
(208) 334-3390

Commission for the Blind
341 West Washington Street,
650 West State, Room 150
Boise, ID 83702
(208) 334-3220

Illinois

Department of Rehabilitation Services
623 East Adams Street
P.O. Box 19429
Springfield, IL 62794
(217) 785-0218

Indiana

Division of Vocational Rehabilitation
Department of Human Services
150 West Market Street
P.O. Box 7083
Indianapolis, IN 46207
(317) 232-1139

Iowa

Division of Vocational Rehailitation
Services
Department of Public Instruction
510 East 12th Street
Des Moines, IA 50319
(515) 281-4154

Department for the Blind
524 Fourth Street
Des Moines, IA 50309
(515) 281-1333

Kansas

Rehabilitation Services
Department of Social and Rehabilitation Services
300 Southwest Oakley, 1st Floor
Topeka, KS 66606
(913) 296-3911

Louisiana

Louisiana Rehabilitation Services
Department of Social Services
P.O. Box 94371
Baton Rouge, LA 70804-9071
(504) 925-4166

Kentucky

Office of Vocational Rehabilitation
Department of Education
Capital Plaza Tower, 9th Floor
500 Metro Street
Frankfort, KY 40601
(502) 564-4566

Department for the Blind
427 Versailles Road
Frankfort, KY 40601
(502) 564-4754

Michigan

Bureau of Rehabilitation
Department of Education
101 Pine Street, 4th Floor
P.O. Box 30015
Lansing, MI 48909
(517) 373-3391

Commission for the Blind
Department of Labor
201 North Washington Square
P.O. Box 30010
Lansing, MI 48909
(517) 373-2062

Minnesota

Division of Vocational Rehabilitation
Department of Jobs and Training
390 North Robert Street, 5th Floor
St. Paul, MN 55101
(612) 296-1822

State Services for the
Blind and Visually Handicapped
Department of Jobs and Training
1745 University Avenue
St. Paul, MN 55104
(612) 642-0508

Mississippi

Rehabilitation Services
P.O. Box 1698
Jackson, MS 39215
(601) 354-7790

Missouri

Division of Vocational Rehabilitation
State Department of Education
2401 East McCarty Street
Jefferson City, MO 65101
(314) 751-3251

Rehabilitation Services for the
Blind
Division of Family Services
Broadway State Office Building
619 East Capital Avenue
Jefferson City, MO 65101
(314) 751-4249

Montana

Rehabilitative Services Division
Department of Social and
Rehabilitative Services
P.O. Box 4210
Helena, MT 59601
(406) 444-2590

Nebraska

Division of Rehabilitation Services
301 Centennial Mall, 6th Floor
P.O. Box 94987
Lincoln, NE 68509
(402) 471-3645

Division of Rehabilitation
Services for the Visually Impaired
Department of Public Institutions
Lincoln, NE 68510
(402) 471-2891

Nevada

Rehabilitation Division
Department of Human Resources
State Capitol Complex
505 East King Street
Carson City, NV 89710
(702) 687-4440

New Hampshire

Division of Vocational Rehabilitation
State Department of Education
78 Regional Drive, Building 2
Concord, NH 03301
(603) 271-3471

New Jersey

Vocational Rehabilitation Services
Department of Labor and Industry
135 East State Street
CN 398
Trenton, NJ 08625
(609) 292-5987

Commission for the Blind and
Visually Handicapped
State Board of Control
Department of Institutions and Agencies
153 Halsey Street
P.O. Box 47017
Newark, NJ 07121
(201) 648-2111

New Mexico

Division of Vocational Rehabilitation
Department of Education
435 St. Michael's Drive, Building D
Santa Fe, NM 87505
(505) 827-3511

Commission for the Blind
Department of Education
PERA Building, Room 205
Santa Fe, NM 87503
(505) 827-4479

New York

Vocational Educational Services for
Individuals with Disabilities
99 Washington Street, Room 1907
Albany, NY 12234
(518) 474-2714

Commission for the Blind and
Visually Handicapped
Department of Social Services
Ten Eyck Office Building
40 North Pearl Street
Albany, NY 12243
(518) 473-1801

North Carolina

Division of Vocational Rehabilitation Services
Department of Human Resources
800 Ruggles, P.O. Box 26053
Raleigh, NC 27611
(919) 733-3364

Division of Services for the Blind
Department of Human Resources
309 Ashe Avenue
Raleigh, NC 27606
(919) 733-9822

North Dakota

Department of Vocational Rehabilitation
State Board of Social Services
State Capitol Building
Bismark, ND 58505
(701) 224-3999

Northern Marinanas

Vocational Rehabilitation Service
P.O. Box 1521-CK
Commonwealth of the Northern Marianas
Saipan, Marinas Islands 96950

Ohio

Rehabilitation Service Commission
400 East Campus View Boulevard
Columbus, OH 43235
(614) 438-1210

Oklahoma

Department of Rehabilitation Services
P.O. Box 36659
Oklahoma City, OK 73136
(405) 424-4311

Oregon

Vocational Rehabilitation Division
Department of Human Resources
2045 Silverton Road, NE
Salem, OR 97310
(503) 378-3850

State Commission for the Blind
535 Southeast 12th Avenue
Portland, OR 97214
(503) 731-3221

Pennsylavania

Bureau of Vocational Rehabilitation
of Labor and Industry
7th and Forster Streets, Room 1300
Harrisburg, PA 17120
(717) 787-5244

Blindness and Visual Department
Services
Department of Public Welfare
300 Capitol Association Building
P.O. Box 2675
Harrisburg, PA 17105
(717) 787-6176

Puerto Rico

Rehabilitacion Vocacional
Division de Rehabilitacion Vocacional
Departmento de Servicios Sociales, Apt. 1118
Hato Rey, PR 00919
(809) 724-3120

Rhode Island

Vocational Rehabilitation
Department of Human Services
40 Fountain Street
Providence, RI 02903
(401) 421-7005

South Carolina

Vocational Rehabilitation Department
1410 Boston Avenue
P.O. Box 15
West Columbia, SC 29171
(803) 822-4300

Commission for the Blind
1430 Confederate Avenue
Columbia, SC 29201
(803) 734-7520

South Dakota

Division of Rehabilitation Services
East Highway 34
c/o 500 East Capitol
Pierre, SD 57501
(605) 773-3195

Services for the Visually Impaired
East Highway 34
c/o 500 East Capitol
Pierre, SD 57501
(605) 773-4644

Tennessee

Division of Vocational Rehabilitation
Department of Human Services
400 Deadrick Street, 15th Floor
Nashville, TN 37219
(615) 741-2019

Texas

Texas Rehabilitation Commission
4900 North Lamar
Austin, TX 78751
(512) 483-4000

State Commission for the Blind
4800 North Lamar
Austin, TX 78756
(512) 467-6300

Utah

Office of Rehabilitation
State Board of Education
250 East Fifth South
Salt Lake City, UT 84111
(801) 538-7530

Vermont

Vocational Rehabilitation Division
Department of Social and Rehabilitation Services
103 South Main Street
Waterbury, VT 05676
(802) 241-2186

Division of Services for the Blind and Visually Handicapped
Department of Social and Rehabilitation Services
103 South Main Street
Waterbury, VT 05676
(802) 241-2211

Virgin Islands

Division of Disabilities and Rehabilitation Services
Department of Human Services
Barbel Plaza South
Charlotte Amalie
St. Thomas, Virgin Islands 00801
(809) 774-2835

Virginia

Department of Rehabilitative Services
State Board of Vocational Rehabilitation
P.O. Box 11045
Richmond, VA 23230
(804) 367-0318

Department for the Visually
Handicapped
397 Azalea Avenue
Richmond, VA 23227
(804) 371-3144

Washington

Division of Vocational Rehabilitation
Department of Social and Health Services
P.O. Box 45340
Olympia, WA 98504
(206) 438-8009

State Services for the Blind
521 East Legion Way
P.O. Box 40933
Olympia, WA 98504
(206) 586-1224

West Virginia

Division of Rehabilitation Services
State Board of Rehabilitation
State Capitol
Charleston, WV 25305
(304) 766-4601

Wisconsin

Division of Vocational Rehabilitation
Department of Health and Social Services
1 West Wilson Street, Room 830
P.O. Box 7852
Madison, WI 53707
(307) 266-5466

Wyoming

Division of Vocational Rehabilitation
Department of Health and Social Services
1100 Herschler Building
Cheyenne, WY 82002
(307) 777-7389

Client Assistance Programs

The Client Assistance Program (CAP) is a type of consumer protection agency available to persons with disabilities who are applying for, or receiving, services from their state Vocational Rehabilitation Agency or any other federally funded Vocational Service Agency. [CAP is independent of the state Vocational Rehabilitation Agency.]

CAP advocates/counselors are available to current and potential consumers of state Vocational Rehabilitation services, and can explain consumer rights and eligibility standards. If an individual is not satisfied with the eligibility decision or services provided by their state's Vocational Rehabilitation system, CAP will (with permission of the individual) attempt to reconcile the problem through mediation and negotiation. If that process is not successful, CAP can help an individual with legal assistance in an administrative review or fair hearing.

For further information on state specific Client Assistance Programs contact:

Arkansas
Advocacy Services, Inc.
(501) 324-9215
(800) 482-1174

Louisiana
Advocacy Center for the
Elderly and Disabled
(504) 522-2337
(800) 662-7705

New Mexico
Protection & Advocacy System, Inc.
(505) 256-3100
(800) 432-4682

Oklahoma
Oklahoma Office of Handicapped Concerns
(405) 521-3756
Protection & Advocacy Agency for
Developmental Disabilities
(918) 664-5883

Texas
Advocacy, Inc.
(512) 454-4816
(800) 252-9108

To locate the CAP in your area, contact your State Vocational Rehabilitation Agency (see pages G.6 - G.17).

Section H

Community-Based Services and Resources for Persons with TBI

Community-Based Services and Resources for Persons with Traumatic Brain Injury

Goal

Whether due to lack of knowledge of where to start, who to call and/or what specific questions to ask, sufficient information about community based services and resources for individuals who have had a traumatic brain injury (TBI) is often incomplete or not known by those who need these facts.

This section is intended to provide a guide for staff members of independent living resource centers, case managers and others interested in identifying services, resources and other characteristics of providers for people who have had a TBI. The worksheet included can be used to develop a resource guide of services and resources for individuals with a TBI in a particular community.

Objectives

1. To provide a checklist which will allow for evaluation of community-based services and resources.

2. To list references, resources, and community contacts for identifying community-based services and resources for persons with traumatic brain injury.

3. To provide examples of standards pertaining to community-based services and resources for living and working after traumatic brain injury.

4. To provide health professionals with information on helping patients/families secure competent legal counsel.

Selected References for Community-Based Services and Resources for Persons with TBI

Articles and Books

Beals MP, Mathews RM, Elkins SR, Jacobs HE. Locating Community Resources for Lifelong Living. Journal of Head Trauma Rehabilitation. 1990; 5(1):31-39.

Catalogue of Educational Materials. Washington, DC: National Head Injury Foundation; 1992.

Costello JJ, ed. The Consumer Connection. Menomonie, WI: University of Wisconsin-Stout, Stout Vocational Rehabilitation Institute, Rehabilitation Research and Training Center; 1991.

Mathews RM. Independent Living as a Lifelong Community Service. Journal of Head Trauma Rehabilitation. 1990; 5(1):23-30.

National Directory of Head Injury Rehabilitation Services: A Reference Guide to Programs and Facilities in the United States Offering Specialized Treatment for Head Injured Persons. Washington, DC: National Head Injury Foundation; 1993.

The Neurolaw Letter. Houston, TX: HDI Publishers; 1994.

O'Hara C, Harrell M. Rehabilitation with Brain Injury Survivors: An Empowerment Approach. Gaithersburg, MD: Aspen Publishers; 1991.

RRX Catalog of Exemplary Programs. Austin, TX: Regional Rehabilitation Exchange, Southwest Educational Development Laboratory; 1992.

Sachs P. A Family Guide to Evaluating Transitional Living Programs for Head Injured Adults. Washington, DC: National Head Injury Foundation; 1988.

Standards Manual for Organizations Serving People with Disabilities. Tucson, AZ: Commission on Accreditation of Rehabilitation Facilities; 1993.

Traphagan JW. Advocating for Funds. Washington, DC: National Head Injury Foundation; 1988.

Identification of Community-Based Services and Resources for Persons with Traumatic Brain Injury

by

Charlotte Ducote, PhD

Sample Resources / Community Contacts

Examples of resource/community contacts to obtain information about services to individuals who have had a traumatic brain injury are listed below. Check phone listings for your area as follows:

- State Vocational Rehabilitation Agency (might be listed in the governmental listings, possibly under Health Department or Social Services agency listings or as Rehabilitation Services (example: Texas Rehabilitation Commission, Louisiana Rehabilitation Services).
- Advocacy centers or organizations (example: Advocacy, Inc. in Texas, Protection and Advocacy System in New Mexico).
- Head Injury Foundation or Association (example: Louisiana Head Injury Foundation, Texas Head Injury Association).
- Independent Living Centers (might be listed under various names, such as New Orleans Resources for Independent Living, Houston Center for Independent Living, etc.).
- Hospitals and rehabilitation centers.
- State Developmental Disabilities Councils.
- Educational resources such as special education departments in public schools, community colleges and universities.

Worksheet

Note: This resource worksheet serves as a guide for those seeking community resources for persons with traumatic brain injury. The information gathered will assist agencies, organizations and individuals such as case managers in compiling resource data about services which are accessible, affordable and appropriate to the needs of persons with TBI.

SECTION ONE: Description of the Provider

1. Name of the agency/organization providing services/resources

   ____

   Address ____

   ____

2. Contact person ____

   Title ____

   Telephone (   ) ____

   Name of director ____

3. Date which the provider began offering the services or resources ____ / ____ / ____

4. Licensure/accreditation (Check all that apply)

   ☐ Commission on Accreditation of Rehabilitation Facilities (CARF)

   ☐ Joint Commission for the Accreditation of Healthcare Organizations (JCAHO)

☐ State Licensure (specify) ______________________

☐ Other (specify) ______________________

5. Status of provider

☐ Private, non-profit

☐ Public, non-profit

☐ Private, for-profit

☐ Other (specify) ______________________

6. Consumer groups(s) served by the provider ______________________

____

____

7. Total number of consumers served by the provider annually ______________________

8. Number of people with TBI served by the provider annually______________________

SECTION TWO: Services and Resources

1. Services and resources provided:

Services/Resources	Yes	No	Comments
Provides information materials on TBI			
TBI support/educational groups (survivors, family)			
Consumer advocacy services			
Legal services			
Peer counseling services			
Personal care assistants			
Independent living information and referral services			
Residential services			
Independent living skills training			
Housing modification			
Vocational services			
Recreational services			
Cognitive training			
Neuropsychological evaluation			
Respite services			
Medical/nursing services			
Therapeutic excercise program			
Medical equipment (loan, purchase, repair)			
Emergency funding/resources			
Others			

2. Does the provider charge for services? ____________________

3. What types of funding are accepted? ____________________

SECTION THREE: Consumer Rights and Empowerment

Consumer Rights	Yes	No	Comments
Is training on advocacy and empowerment provided for consumers?			
Is there consumer input in treatment program, planning of service/resource utilization, etc?			
Are consumers informed of other services, resources and providers?			
Can the consumer receive copies of his/her reports, service plans, etc? (As applicable)			

SECTION FOUR: Safety and Security (If applicable)

Safety and security	Yes	No	Comments
Are there security systems in place? (As applicable to a residential facility)			
Are there procedures for medical, fire, disaster, or other emergencies?			

SECTION FIVE: Outcome Information (If applicable) - (Vocational Rehabilitation programs, transitional living facilties, day treatment programs)

1. Outcomes as well as the number in each outcome category achieved by consumers who used services/resources from this resource in the last year:

Outcome	#Who Achieved This Outcome
a. ______	______
b. ______	______
c. ______	______

2. What follow-up is done and how often is this done? ______

______

______

SECTION SIX: Service Provider References

Please provide the names and telephone numbers of at least three consumers who have utilized your services.

Name	Telephone Number
______	( ) ______
______	( ) ______
______	( ) ______
______	( ) ______
______	( ) ______

Regional Rehabilitation Exchange Project

Excerpt from Region VI SEDL/RRX Manual (1992)

Background And Purposes Of The RRX Project

The Regional Rehabilitation Exchange (RRX) Project was initiated in March 1983, when it first received funding from the National Institute on Disability and Rehabilitation Research (NIDRR). The RRX surveys the rehabilitation and independent living community for programs and practices that demonstrate and can document especially effective service delivery to persons with disabilities and can serve as models for other agencies and organizations.

Using a detailed evaluation procedure that includes peer review, the RRX validates rehabilitation and independent living programs that are especially effective and recognizes them formally as exemplars. These exemplary program models generally demonstrate a high success rate, surpass established performance standards, show significant and stable results, are cost-effective, and include adaptable or transportable components.

One of NIDRR's goals is to promote the wide-spread use of proven, effective programs and practices among rehabilitation and independent living professionals. To address this goal, the RRX publishes and disseminates an annual *Catalog of Exemplary Programs and Practices* that contains individual summaries describing each program receiving exemplary designation.

The *Catalog* is provided to a wide audience of rehabilitation and independent living administrators, practitioners, and consumers interested in learning about the exemplary program models. In some instances, the RRX can broker and provide in-depth technical assistance to agencies or organizations interested in adopting or adapting an exemplary program model.

By identifying exemplary program models, informing the rehabilitation and independent living community about their operations and outcomes, and assisting organizations interested in implementing exemplary program model components, the RRX hopes ultimately to contribute to the continued improvement in services provided to persons with disabilities.

Scope Of The RRX Project

The RRX generally concentrates on identifying exemplary program models from the five states in Rehabilitation Services Administration (RSA) Region VI: Arkansas, Louisiana, New Mexico, Oklahoma, and Texas. Although the project is confined to providing technical assistance only to agencies and organizations within this region, the project's Peer Review Advisory Council (PRAC) may at times identify exemplary program models from other parts of the country. Out-of-region exemplars are identified when doing so would supplement existing in-region models available to offer technical assistance.

The four service area categories, or "core areas", in which programs are reviewed and identified as exemplary currently include:

- Job placement services.
- Transitional services.
- Supported employment services.
- Independent living services.

Definitions of these categories are provided below.

Job Placement Services - include any services targeted to the placement of persons with disabilities in competitive employment positions. Such services may be targeted to persons with a wide range of disabilities, including learning disabilities, mental retardation, mental illness, and/or physical disability. "Competitive employment positions" refers to employment positions that are available in the community and that could be filled by any qualified applicant, with or without a disability.

Transitional Services - include any short-term activities and/or related services that promote the transition of persons with disabilities to competitive working life. Training activities are designed to provide clients with a specific set of skills that can be used to secure and maintain competitive employment positions. "Short-term" refers to a period usually not more than 12-18 months; however, the critical factor is not a specific time period but the fact that, at some point, the client possesses the skills to work competitively and independently, without any ongoing, special services provided after job placement. Transitional Services may be targeted to persons with a wide range of disabilities, including learning disabilities, mental retardation, mental illness, and/or physical disabilities. Such services may be offered through secondary or post-secondary schools or community-based programs and facilities for adult clients.

Supported Employment Services - are designed to enable clients with severe disabilities to secure and maintain employment. Such services generally provide placement, training, and ongoing, long-term support that is necessary for clients to continue employment. These programs, then, do not lead to unassisted competitive employment; they are designed for persons with disabilities so severe that they are not eligible for traditional vocational rehabilitation services. Within this category, exemplary program models may focus on one or more of the following specific elements of supported employment services:

- Innovative, creative funding arrangements.
- Services for specific disability groups.
- Characteristics of effective job coaching.

Independent Living Services - include a broad range of services designed to improve the quality of life for persons with severe disabilities via organizations and programs that are controlled by the consumers of those services themselves. Such services may include: (1) housing, (2) transportation/mobility, (3) living skills, (4) counseling, (5) community integration, and/or (6) employment-related services. Each of these areas is described below.

1. **Housing services -** may include information and referral services; assistance with financial arrangements; provision of accessible housing; skills development focused on home safety, cleaning and maintenance, in-home mobility, and/or food planning and preparation; and any other services necessary for the person with a severe disability to obtain and maintain a desired level of independence in the broad area of housing.

2. **Transportation/mobility services -** involve the development of personal and community resources to facilitate and increase mobility. Services may range from assistance with vehicle modification or purchase of a modified vehicle, to assurance of appropriate public transportation, to skills development in orientation and mobility.

3. **Living skills services -** include training and assistance related to daily living needs. Services may include skills development related to communication, personal hygiene and dress, and problem-solving; provision of adaptive equipment or devices; and/or specialized training for personal attendants.

4. **Counseling services -** may range from peer support services to ongoing individual counseling aimed at development of specific behaviors. Group counseling, personal and social adjustment counseling, sexuality counseling, and/or referral to appropriate professional counseling resources may be provided within this category.

5. **Community integration services -** may involve a range of activities, including individual/group advocacy, recreation, consumer skills development, and/or training in basic academic skills.

6. **Employment-related services -** address a variety of issues related to employment of persons with severe disabilities. They may include direct employment services such as job or career development, job placement, or supported employment services; training or support related to job modification, retention, or mobility; and/or community and employer awareness efforts focusing on the benefits of hiring persons with severe disabilities.

The RRX Validation Process

Validation is a way of identifying those rehabilitation programs that are exemplary or outstanding in their results. It utilizes an evaluation system that applies a set of criteria to descriptive program information together with an onsite observation to determine whether the documented program effects are truly outstanding.

The schematic on page H.15 illustrates the sequence of events that constitute the RRX validation process. The process is begun when a potential exemplary program is nominated, either by persons within that program or by an outside third party well-acquainted with the program. RRX staff contact the nominees to determine whether they meet the validation prerequisites and if they desire to proceed with the validation process. If so, the nominee completes an Information Request Form and forwards it to RRX staff, who analyze it by applying a weighted information scoring system.

After evaluating a program in regard to the data provided in the completed Information Request Form and according to the critical factors previously described, RRX staff may eliminate a nominated program from further consideration.

Reasons for eliminating a program at this point might include factors such as:

- Failure of the nominated program to correspond with one of the core areas identified by the Peer Review Advisory Council.

- Insufficient client outcome data, however defined by the program.

- Inadequate descriptions of program operation.

- Incomplete client follow-up data.

If a program nominee is eliminated from further consideration, RRX staff will provide a written notification to program representatives, and no onsite visit is planned. If an application of the evaluation weighting criteria indicates that the nominated program would be reviewed further, an onsite visit is scheduled and the remaining steps (5-9) of the RRX validation process are followed.

The RRX has published a *Validation Manual for Exemplary Programs and Practices* for each program core area. These manuals contain more detailed information concerning the validation process and specific examples to facilitate completing an Information Request Form. Copies of any of the manuals may be obtained by contacting the Regional Rehabilitation Exchange.

Prerequisites For Validation

Each rehabilitation or independent living program of practice nominated for recognition as exemplary must meet a set of prerequisites. Before further program evaluation can occur, each nominated program must first assure that it:

- Has clearly defined program goals, objectives, and activities.
- Is performing activities that correspond to one of the current RRX core areas.
- Has been in existence for at least two years prior to consideration as exemplary by the RRX Peer Review Advisory Council, and expects to continue operation for at least one year past the time of annual Catalog publication (July or August of each year), or has received a waiver from the RRX Peer Review Advisory Council.
- Meets necessary state/federal certification or accreditation requirements, where applicable.
- Can demonstrate program effectiveness through accumulated documentation of program services and client outcomes.
- Has kept records of expenditures for a recent twelve-month period in the categories of personnel, facilities, equipment, and materials.
- Is able to provide descriptive program information through the Information Request Form and an onsite visit.
- Is willing to share descriptive information with interested rehabilitation or independent living professionals through telephone, letter, or onsite visits.

- Will keep records of these contacts and report periodic summaries to the RRX.

- Is willing to act as a technical assistance consultant to assist other organizations wishing to adopt or adapt the exemplary program model to their own service delivery systems.

Staff of the nominated program/practice will conduct a self-assessment for compliance with these prerequisites. If all requirements are met, nominated program staff will proceed in the validation process by completing the Information Request Form and returning it to the RRX for analysis.

Criteria For Validation

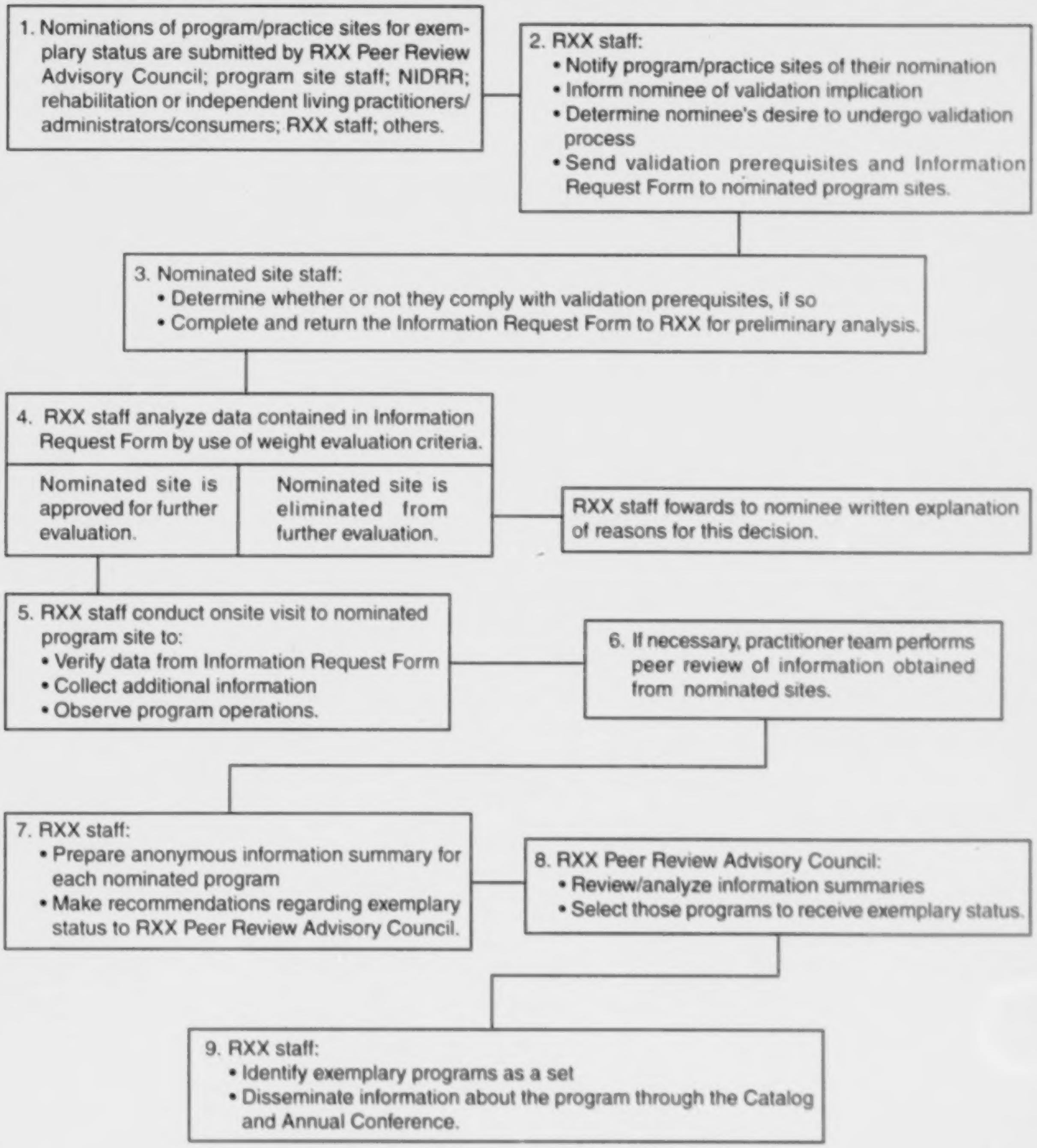
Since its inception in March 1983, the RRX has developed, expanded, and refined the validation process by which exemplary rehabilitation and independent living programs are identified. The criteria used for validation have evolved into a system consisting of ten separate critical factors. These factors are related to a weighting system that assigns to each a specific weight relative to its importance in the evaluation process. The RRX Peer Review Advisory Council has adopted these criteria as being those characteristics of critical importance to be considered in the classification of all exemplary programs. The table on the next page presents and discusses each critical factor.

Assessment Of Critical Factors

In reviewing the data contained in the Information Request Form, RRX staff analyze specific characteristics to determine the extent to which the nominee can provide descriptive information that addresses each of the ten critical factors. The RRX Peer Review Advisory Council has not established absolute expectations or standards for information relating to each of the ten critical factors. For example, it is not absolutely necessary that all factors be addressed at the same high level for a program to achieve exemplary status. Conversely, addressing only a few factors extensively, to the relative exclusion of others, may jeopardize the program's designation as exemplary.

During the peer review of nominated programs, available information is compared on all programs being considered for exemplary status at any one time. From this total set, a limited number of programs are selected as exemplary depending upon the relatively cross-program rankings resulting from the review and comparison process.

The RXX Validation Process



1. Nominations of program/practice sites for exemplary status are submitted by RXX Peer Review Advisory Council; program site staff; NIDRR; rehabilitation or independent living practitioners/administrators/consumers; RXX staff; others.

2. RXX staff:
   - Notify program/practice sites of their nomination
   - Inform nominee of validation implication
   - Determine nominee's desire to undergo validation process
   - Send validation prerequisites and Information Request Form to nominated program sites.

3. Nominated site staff:
   - Determine whether or not they comply with validation prerequisites, if so
   - Complete and return the Information Request Form to RXX for preliminary analysis.

4. RXX staff analyze data contained in Information Request Form by use of weight evaluation criteria.

Nominated site is approved for further evaluation.

Nominated site is eliminated from further evaluation.

RXX staff fowards to nominee written explanation of reasons for this decision.

5. RXX staff conduct onsite visit to nominated program site to:
   - Verify data from Information Request Form
   - Collect additional information
   - Observe program operations.

6. If necessary, practitioner team performs peer review of information obtained from nominated sites.

7. RXX staff:
   - Prepare anonymous information summary for each nominated program
   - Make recommendations regarding exemplary status to RXX Peer Review Advisory Council.

8. RXX Peer Review Advisory Council:
   - Review/analyze information summaries
   - Select those programs to receive exemplary status.

9. RXX staff:
   - Identify exemplary programs as a set
   - Disseminate information about the program through the Catalog and Annual Conference.

In their selection of exemplary programs models, members of the RRX Peer Review Advisory Council keep in mind one of the main priorities of the project: to develop a pool of technical assistance resources representing a wide range of diverse approaches to rehabilitation and independent living service delivery issues.

There may be a number of in-region programs conducting similar activities and producing similar sets of outcomes. It is probable that not all examples of like programs will be recognized as exemplary, although several may demonstrate worthy program outcomes. For the same reasons, out-of-region programs offering different services and producing sets of outcomes different from those documented by in-region programs may be identified as exemplary when such an addition to the available technical assistance resource pool would be favorable.

Selecting a Lawyer

by

J. Sherrod Taylor, JD

Introduction

People with traumatic brain injury (TBI) and/or their families must make many important decisions in the early days following injury. If the trauma event which caused the injury is one which later may become the subject of civil litigation (e.g., an on-the-job injury giving rise to a workers' compensation claim or a tortious injury upon which a personal injury lawsuit may be brought), the selection of a lawyer becomes significant. However, that decision is frequently one which is placed on the "back burner" while seemingly more pressing questions regarding treatment and rehabilitation are addressed.

Yet, obtaining the *right* lawyer as soon as possible may be a key factor in determining the amount of money which could become available to injured persons and their families in the future. Money obtained through workers' compensation and/or personal injury litigation is used not only to compensate TBI persons for lost income and pain/suffering, but also for funding programs of treatment and rehabilitation.

O'Hara and Harrell (1991) point out that "choosing an attorney can be a difficult process under the best of circumstances and is certainly not made any easier as the patient is recovering from trauma of brain injury." (Please note that the words "lawyer" and "attorney" can be used interchangeably). However, knowledgeable health care providers, discharge planners and case managers may assist people with TBI and their families in this process. This chapter addresses the issues which care providers and patients/families should consider during the quest to secure competent legal counsel. It contains several checklists which can be used successfully to screen cases and potential lawyers. It also presents insight into the civil litigation process. Concerned health professionals should consider employing the techniques described here and may want to distribute copies of this chapter to injured patients and their families.

First Task

The first task which care providers, survivors and families undertake is to determine whether or not the factual circumstances surrounding a particular injury may give rise to a legal cause of action. The following checklist will be helpful in making this determination since it poses threshold questions which should be answered affirmatively.

- Did the patient's brain injury result from trauma?

- Was the trauma sustained while the patient was working on-the-job? (If "yes," the patient or family should be advised to consult an attorney who is familiar with TBI and workers' compensation cases.)

-or-

- Did the TBI result from a motor vehicle collision, fall, recreational incident, defective product or any other circumstance which may give rise to civil liability? (If "yes", the patient or family should consult a lawyer who has expertise in handling personal injury cases involving TBI.)

Thus affirmative answers to these simple questions means that a lawyer should be consulted as soon as possible.

Lawyers And TBI Litigation

Many lawyers hold themselves out to the public as specialists in workers' compensation and/or personal injury cases. For example, the telephone book of every town or city contains listings for such attorneys under such headings as: "Attorneys - Trial Practice - Personal Injury & Wrongful Death." Some lawyers advertise their services on television or in other media. But finding the *right* attorney may be a difficult task and may require much effort.

Because TBI presents many complex issues, many lawyers are not qualified to handle the intricacies of these cases. Fortunately, a new type of lawyer is responding to the challenges of TBI litigation. The *neurolawyer* is one who, through interest, education, and training, has developed special expertise in representing clients with TBI. Many of these lawyers have received training through continuing legal education seminars sponsored by organizations such as the National Head Injury Foundation (NHIF). Building upon this training, these lawyers have taken their knowledge into the courtroom and have obtained awards and out-of-court settlements in the substantial amounts needed to provide for the care and maintenance of their TBI clients. But, *neurolaw* is a new field. In fact, the term "neurolaw" was first coined in 1991, by this author and his colleagues.

Referral Resources

Health care providers, survivors and families have several referral resources available for use in selecting competent legal counsel. The National Head Injury Foundation's *Directory of Head Injury Rehabilitation Services* is a primary source of pertinent information. This directory contains listings of facilities and individuals who deal on a regular basis with TBI concerns. Because lawyers are an integral part of the multidisciplinary TBI team, this directory includes biographic data on attorneys who specialize in representing TBI persons and their families. This publication is an essential tool for health care providers, discharge planners, case managers and survivors/ families.

Often physicians, neuropsychologists and other care providers have personal knowledge regarding specific attorneys who work in this field. When this is the case, that knowledge should be shared with patients and families. Moreover, many states, through their departments of human services or similar agencies, maintain "head injury registry" services. State registry agencies, too, may be aware of particular attorneys with expertise in TBI litigation.

Initial Screening Process

After obtaining a list of qualified neurolawyers, the TBI survivor or family member should contact those attorneys by telephone. Most neurolawyers offer telephone consultation at no charge. Some even provide national toll free numbers so that potential clients do not have to undergo the expense of calling. During the initial telephone conference, the injured person or family member may begin to screen the prospective attorneys to determine whether or not they possess the skill and expertise to handle their case. The attorney's responses to the questions listed below will be of great assistance in learning whether or not an office conference with that lawyer is in order. Among the questions that should be asked are:

- Have you successfully represented in the past persons with injuries of the brain or spinal cord?
- How much of your practice is devoted to such cases?
- Are you a member of NHIF and/or one of its state associations?
- Have you lectured and/or authored professional publications on the subject of TBI?
- Are you a member of professional legal organizations (e.g., American Bar Association, Association of Trial Lawyers of America, state bar association, etc.)?
- Have you tried TBI cases and obtained successful results?
- Have you settled TBI cases out-of-court with success?
- Do you work often with neuropsychologists, physiatrists, rehabilitation specialists, and life care planners?

- Do you favor structured settlement in TBI cases (so that long-term financial security may be obtained)?

- Do you carry a policy of legal malpractice insurance?

Bona fide neurolawyers will not be reluctant, offended, or embarrassed to answer these questions.

Conference With Attorney

Once one or more attorneys have been found to be "qualified" using the above screening procedure, the patient or family member should arrange to meet with the prospective lawyer(s). During the initial office conference, the survivor or family member should further scrutinize the attorney prior to signing an attorney-client contract. The following questions must be answered:

- Does the attorney appear to have understanding of the TBI field?

- Does the attorney appear cognizant of the problems associated with TBI?

- Does the attorney have in the office models, medical illustrations, and library materials pertaining to TBI?

- Does the attorney demonstrate *confidence* and ability to represent TBI persons?

- Does the attorney appear to possess the appropriate "bedside manner" and personal commitment to work with TBI clients?

- Is the attorney honest in appraisal of the strengths and/or weaknesses of the particular case?

- Will the attorney's workload permit undertaking a substantial, new case?

- Does the attorney have other lawyers and staff who may assist in handling the case?

- Is the attorney competent to handle, not only the personal injury or workers' compensation litigation, but also the other facets of TBI such as insurance and social security matters?

- Is the attorney truly interested in working on this particular legal matter?

Retaining An Attorney

After the patient or family has identified a qualified neurolawyer, that attorney should be retained. In workers' compensation cases, most states have laws governing the specific requirements applicable to the attorney-client contract. Often the terms of this agreement are set forth in detail - including provisions establishing the manner in which attorneys' fees may be charged.

Traditionally, personal injury attorneys work on a contingency fee basis. That is, they do not receive payment for their fees directly from the client, but rather they take a percentage of the total amount recovered from the defendant or the defendant's insurer as their fees. Percentages vary from case to case - depending upon the complexity of the case and the probability of a successful outcome.

The outcome of workers' compensation cases usually turns upon establishing: (1) that the TBI arose "out of employment" and (2) the future care needs of the survivor. Since workers' compensation is a 'no-fault' system, it is *not* necessary to prove that an employer was *negligent* in causing the worker to be injured. The long-term care needs of the client, therefore, become the focus of legal inquiry.

Personal injury (PI) litigation is different from workers' compensation cases. In PI cases, legal responsibility or liability is necessary for successful recovery of monetary damages. Usually these cases are predicated upon the *negligence* of the defendant as the cause of the brain injury. For example, if the injury resulted from a motor vehicle collision where the defendant ran a stop sign, then a successful case can be maintained because violation of a stop sign statute constitutes negligence as a matter of law. Sometimes, TBI results from a defective product which causes injury. In those instances the legal doctrine of "product liability" forms the basis for the litigation.

Neurolawyers use a three-step analysis to determine the likely outcome of the case and to set their contingency fees. First, they examine the *liability* aspects of the case. If the potential defendant is clearly responsible for causing the injury and if the survivor bears no responsibility for causing the injury, then the attorney will usually accept the case for a contingency fee in the 33 1/3% to 40% range. More difficult liability situations will lead the lawyer to charge a higher percentage. Under no circumstances should the contingency fee exceed 50%. Expenses and the costs of litigation are generally advanced by the attorney, but these ultimately will be paid by the client out of the client's share of the proceeds at the end of the case.

Second, the neurolawyer evaluates the *extent of injury*. Obviously, a greater recovery may be expected in cases with more serious injuries which require extensive periods of treatment and which result in the client being permanently disabled to at least a partial degree.

Third, the neurolawyer examines the *ability of the defendant to pay* for the injury caused. Usually, but not always, the limits of potential monetary recovery are set by the amount of insurance coverage available to the defendant. The attorney's estimate of available insurance coverage may be the determining factor in whether or not the attorney will accept the case. Even if the injury is substantial, when the availability of funds to pay for the injury is limited, the attorney may decline the case.

However, if liability is good, injury is apparent, and insurance funds are plentiful, the neurolawyer will probably accept the case. At this point the attorney-client contract is signed to initiate representation in the case.

Plan For Action

After the neurolawyer has agreed to represent the client, a specific plan of action must be formulated. The attorney should advise the survivor and family of the litigation events which will take place. A timetable for these events should be established. Litigation events in catastrophic injury cases may include: obtaining complete medical, employment, school and military records; establishing contact with the defendant and the defendant's insurer; attempting to settle the case prior to filing a claim or lawsuit; filing the claim or lawsuit; pursuing discovery of the facts by interrogatory questions, requests for the production of documents, depositions, etc.; attempting to settle the case before trial; and trial of the case.

Conclusion

By becoming aware of the process described above, health care providers may provide valuable assistance to survivors and their families when they require legal services. By following the suggestions outlined here, persons with brain injury and their families likely will be successful in securing the representation they need to obtain favorable financial outcomes in these cases. In appropriate cases successful prosecution can lead to the recovery of ample proceeds for use in compensating for income loss and pain/suffering and in funding a lifetime of care, treatment and rehabilitation.

Reference

O'Hara CC, Harrell M. Rehabilitation With Brain Injury Survivors: An Empowerment Approach 90. Gaithersburg, MD: Aspen Publishers, Inc.; 1991.

Section I

Substance Abuse Issues for Persons with TBI

Substance Abuse Issues for Persons with TBI

Goal

This section will provide an overview of substance abuse issues in the area of traumatic brain injury (TBI). The materials will discuss the substance abuse issue as well as specialized treatment models for addiction in persons with TBI.

Objectives

1. To provide epidemiological information on the extent of the problem of substance abuse in the TBI population, what alcoholism is and some reasons for substance abuse decline in some survivors post-injury.

2. To describe the Alcoholics Anonymous/Narcotics Anonymous models of substance abuse intervention, the advantages and disadvantages of these models when used in the treatment of persons with TBI.

3. To identify components of a substance abuse program that are appropriately designed for persons with both substance abuse problems and TBI.

Selected Resources for Substance Abuse Issues for Persons with TBI

Articles and Books

Alterman A, Tarter R. Relationship Between Familiar Alcoholism and Head Injury. Journal of Studies on Alcohol. 1985; 46:256-258.

Blackerby W, Baumgarten A. A Model Treatment: Program for the Head-Injured Substance Abuser: Preliminary Findings. The Journal of Head Trauma Rehabilitation. 1990; 5(3):47-59.

Brody R. At Risk of Head Injury and Substance Abuse. Headlines. 1991; 2(2):4-5.

Corthell D, Brown J. Substance Abuse as a Coexisting Disability. Menomonie, WI: University of Wisconsin-Stout, Research and Training Center Stout Vocational Rehabilitation Institute; October, 1991.

Heinemann A. Alcohol and Other Drug Abuse Prevention for People with Traumatic Brain and Spinal Cord Injuries. Chicago, IL: Midwest Regional Head Injury Center for Rehabilitation and Prevention, and the Illinois Prevention Resource Center; 1992.

Jones G. Alcohol Abuse and Traumatic Brain Injury. Alcohol Health and Research World. 1989; 13(2):105-109.

Kreutzer J, Doherty K, Harris J, Zasler N. Alcohol Use Among Persons with Traumatic Brain Injury. The Journal of Head Trauma Rehabilitation. 1990; 5(3):9-20.

Kreutzer J, Harris J. Model Systems of Treatment for Alcohol Abuse Following Traumatic Brain Injury. Brain Injury. 1990; 4(1):1-5.

Kreutzer J, Marwitz J, Wehman P. Substance Abuse Assessment and Treatment in Vocational Rehabilitation for Persons with Brain Injury. Journal of Head Trauma Rehabilitation. 1991; 6(3): 12-24.

Marwitz J, Kreutzer J. Annotated Bibliography of Articles on Alcohol Abuse Among Brain Injured and Spinal Cord Injured Patients. Richmond, VA: Virginia Commonwealth University; Rehabilitation Research and Training Center on Severe Traumatic Brain Injury; 1991.

Miller L. Neuropsychology, Personality and Substance Abuse: Implications for Head Injury Rehabilitation. Cognitive Rehabilitation. 1989; 7(5):26-31.

Mitiguy J. Cycles of Abuse: Alcohol and Head Trauma. Headlines.1991; 2(2):2-9.

Professional Council Task Force on Substance Abuse. Substance Abuse Task Force White Paper. Washington, DC: National Head Injury Foundation: April 1988.

Picard M, Paluck R, eds. Traumatic Brain Injury and Substance Abuse: A Reference and Resource Guide. U.S. Department of Education: Rehabilitation Services Administration;1991.

Rehabilitation Research and Training Center on Severe Traumatic Brain Injury. Substance Abuse Assessment and Education Kit. Richmond, VA: Virginia Commonwealth University; Rehabilitation Research and Training Center on Severe Traumatic Brain Injury; 1991.

Seaton J, David C. Family Role in Substance Abuse and Traumatic Brain Injury Rehabilitation. Journal of Head Trauma Rehabilitation. 1990; 5(3):41-46.

Shipley R, Taylor S, Falvo D. Concurrent Evaluation and Rehabilitation of Trauma and Substance Abuse. Journal of Applied Rehabilitation Counseling. 1990; 21(3):37-39.

Sparadeo F, Gill D. Effects of Prior Alcohol Use on Head Injury Recovery. Journal of Head Trauma Rehabilitation. 1989; 4(1):75-82.

Sparadeo F, Strauss D, Barth J. The Incidence, Impact, and Treatment of Substance Abuse in Head Trauma Rehabilitation. Journal of Head Trauma Rehabilitation. 1990; 5(3):1-8.

Wasco J. Attacking the Problem Before it Starts. Headlines. 1991; 2(2):20.

A manual entitled Alcohol, Drugs and Brain Injury, A Survivor's Workbook , by Robert Karol, PhD and Frank Sparadeo, PhD, is available free of charge by calling
(800) CARE TBI x3074.

Organizations

National Head Injury Foundation (NHIF)
1776 Massachusetts Avenue, NW
Suite 100
Washington, DC 20036
(202) 296-6443
Family Help Line: (800) 444-NHIF

NHIF has chapters in many states. See pages A.3 - A.4 for an expanded list.

To locate additional resources contact your state Governor's Committee on People with Disabilities. Or obtain a State Resource Sheet from:

National Information Center for Children and Youth with Disabilities
P.O. Box 1492
Washington, DC 20013
(703) 893-6061
(800) 999-5599
TDD: (703) 893-8614

National Institute of Neurological Disorders and Stroke
Building 31, Room 8A06
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5924

Twelve Steps Of Alcoholics Anonymous (For people with English as a second language)

1. We admitted that alcohol was more powerful than ourselves. We admitted that we could not control our lives.

2. We began to believe that a power stronger than ourselves could make our minds healthy again.

3. We decided to let God take care of our minds and our lives. We chose our own idea of who God is.

4. We made a complete list of our personality problems. We were not afraid to make this list (inventory).

5. We told God and another person about our personality problems.

6. We were completely ready to let God take away all of these personality problems.

7. We humbly asked God to remove our weaknesses.

8. We made a list of all the people we hurt in the past. We became ready to tell them we were sorry and to correct past damage.

9. We said we were sorry to the people we hurt, and we tried to correct the past damage, if possible. But we did not do this if it would hurt them or other people.

10. We continued to look at the strong and weak parts of our personality. When we were wrong, we quickly admitted it.

11. We used prayer and meditation to improve our contact with God (the idea of Him that we chose). We prayed only to know His way; and we prayed only for the power to live His way.

12. Our spirit grew because we used these twelve steps, so we tried to tell other alcoholics about the steps. And we tried to use these steps in everything we did.

A Model Treatment Program for the Head-Injured Substance Abuser: Preliminary Findings

by

W.F. Blackerby, PhD, and Ann Baumgarten, MA, CRC

Reprinted in its entirety from the Journal of Head Injury Trauma Rehabilitation. 1990; 5(3):47-59.

This article describes a treatment program designed to provide holistic rehabilitation services to persons with traumatic brain injury who are diagnosed as chemically abusive or dependent. Unique aspects of the cognitive and behavioral sequelae of brain injury mandate a nontraditional approach to effective treatment of substance abuse. Program structure and components, staff development, service delivery, and reimbursement system are described. Case examples and group data are presented for the small sample of programs for this population. The importance of third-party reimbursement and support for the program cannot be overstated for such programs to be successful.

The extent of drug and alcohol abuse and dependency problems, both generally and before and after Traumatic Brain Injury (TBI), are well described elsewhere in this issue. This article describes the development of, operation of, and initial outcome data from a postacute rehabilitation program designed specifically for clients with dual diagnoses of chemical abuse or dependency and TBI.

As a starting point in program development, the National Head Injury Foundation White Paper report lists several necessary program components, including staff training, active family involvement, Alcoholics Anonymous (AA) and Narcotics Anonymous (NA) support groups, counseling, environmental control, behavioral intervention, and psychopharmacologic management.[1] Also included in this document is a restatement of the AA's "12 Steps" in language that may be more comprehensible for persons with brain injury.

Weiss and Frankel[2] describe the need for a holistic approach to rehabilitation with dual diagnosis clients. Unfortunately, they define holistic rather narrowly as including only vocational and independent living skill development, omitting such issues as relationships, intimacy, community, and spirituality in their definition. Newton, Elliott, and Meyer[3] have described a structured workplace model for chronically disabled persons with abuse and dependency problems. This model emphasizes the role of work environments for alcohol or drug users in access reduction, stimulus control, and reinforcement. Jones[4] and Grant[5] have described the cognitive and neuropsychological aspects of TBI that must be considered in developing effective treatment for the dual diagnosis client. Bradley, in this issue, lists factors such as staff training, treatment experience, program philosophy, access to AA and NA meetings, extent of family involvement, aftercare services, and accommodation as important program components for cognitive impairment.

Overall, this literature suggests the following principal elements for effective rehabilitation programming:

- Initial and ongoing staff training in both chemical abuse and dependency and behavioral rehabilitation.
- Family system based treatment.
- Close involvement with AA or NA support groups.
- Stimulus control techniques.
- General behavior change intervention methods.
- Pharmacologic support when indicated.
- Whole person treatment philosophy.
- Structured aftercare programming.
- Accommodation for cognitive impairments.

These elements were the starting point in designing the program described.

Program Development

With these basic elements as a foundation, a program development team was formed to determine the treatment philosophy, staff training needs, curriculum, and operational structure for a dual diagnosis treatment program to be named Rebound Lifestyle Adjustment Team (RELATE). The overall goal of the program was total abstinence rather than controlled use. The program was to be kept small, with a capacity of no more than eight clients. Physically, the program was housed in a section of a residential postacute brain injury rehabilitation program in Tennessee. All services in both the RELATE and the TBI rehabilitation programs for RELATE clients were provided within an area of the facility set aside for the program.

Family involvement was seen as crucial to long-term successful outcome. Families were encouraged to attend core lectures and community meetings as they were able. Individual, group, and family counseling services were provided as well. Admission criteria included:

- Age over 18.
- Diagnosis of TBI.
- Cognitive level VII or higher on the Rancho scale.
- Functional communication system.
- Evidence of chemical abuse or dependency, preinjury or postinjury.
- Some awareness of the negative impact of the chemical use.

Program fees were the same as those for all other clients in the facility.

A decision was made to provide varying degrees of intensity of chemical dependency rehabilitation, depending on client needs.This flexibility was possible because the program was conducted within a residential postacute rehabilitation facility. In addition to servicing clients with identified dependency and abuse problems, the program provided prevention services to clients judged to be at risk for further chemical abuse or dependency. Clients who could be served ranged from those who needed only specific services provided by the program, such as education or counseling, to those who require the complete range of services at a high-intensity level. Therefore, clients in the program and those within the facility but not in the RELATE program had varying degrees of intensity of participation in both the RELATE program and the brain injury rehabilitation program.

THE AA / NA Model In Brain Injury Rehabilitation

The AA/NA model was chosen as the philosophical and applied foundation for the program because of its record of success in treatment, emphasis on personal lack of control over dependency and abuse, peer support, and the spiritual emphasis.[6] Furthermore, AA and NA support groups are widely accessible in this country and provide an established source of community-based after-care services. It was decided that participation would be within the regular community-based AA or NA groups rather than facility-based groups because clients were to be discharged from the RELATE program with an after-care plan that included participation in these community-based groups. It was felt that the earlier the clients became integrated into this structure, the easier it would be for them to continue in a similar group in their home community. Staff coaches accompanied clients to these meetings, within the AA and NA guidelines, to assist clients in participating and learning to integrate relevant material from the meetings into the facility treatment program.

A primary feature of the AA-NA model is that it depends on insight and verbal discourse in peer group counseling situations. This method is unsuitable for any brain-injured clients because of the high incidence of frontal lobe dysfunction, which impairs the capacity for insight into psychodynamic and behavioral factors related to abuse and dependency. Moreover, memory impairment in individuals with brain injury greatly limits the ability to acquire and retain an ongoing awareness of feelings and behavior as well as any insight that may have developed. In addition, it may be difficult in the group treatment setting for the person with brain injury to inhibit impulsivity, attend selectively, process auditorially, and respond verbally, given the frequency and diversity of cognitive deficits in this population.

Cognitive-Behavioral Approach

To compensate for these difficulties, a number of treatment and program design elements were developed. The overall orientation of the program was to function as a cognitive-behavioral client training approach to rehabilitation through teaching and reinforcing self-awareness, knowledge, and abuse or dependency avoidance behavior.

Considerable time was devoted to identifying, in the home environments of the client and on community outings, stimuli that served to prompt chemical abuse. Usually, the stimulus consisted of social or work-related friends, access to drugs or alcohol, money (for purchase), or lack of structured time. Treatment and discharge planning was then focused on addressing these elements for each client. Clients received verbal praise during the community outings for identifying advertisements or other environmental stimuli promoting the use of chemicals. They received training in structuring their schedules to eliminate the free time that elicited abuse behavior. Managing peer pressure also was a focus of the training. Role play and videotaping were used to create situations in which clients would be urged to use drugs and alcohol, with training in responses to that pressure. Training in budgeting money was emphasized so that money available for purchase of drugs and alcohol was controlled by the client.

Throughout the program, client control was emphasized. Clients were reinforced when demonstrating control over their lives and responsible decision making. The sense of self-control was presented in contrast with the sense of being controlled by the abused chemicals. Verbal and written affirmations were used to establish the basis for attitudinal changes regarding the use of chemicals. Many of these affirmations were standard statements used in AA, so that continuity and continued reinforcement could be maintained in the aftercare environment.

Treatment group size was limited to four. Multimodal group treatment methods were employed, and staff were trained and monitored in keeping verbal interactions simple and concrete.Multimodal methods included the use of role play, visual aids, videotaping, peer modeling, and coaching with sessions. In addition, the pace of instruction, practice, and training was reduced to compensate for the slower learning and reduced intellectual capacity of most clients. The one adolescent in the program attended age-appropriate groups in counseling, in which topics discussed included completing school, relationships with peers and parents, and "how to be a teenager," rather than the adult group topics such as independent living and remaining sober at work.

The treatment schedule provided considerable repetition and highly intensive treatment. Recent research has shown that treatment intensity is an important factor in length of stay and successful outcome.[7,8] Client time was structured from waking until sleeping to provide maximum intensity treatment. There were two education and discussion sessions and two group counseling sessions per day, two daily community meetings in the facility and AA or NA meetings in the community, structured exercise and leisure time, and traditional rehabilitation therapies as needed. Each client had a primary staff member assigned to develop a personal relationship and provide advocacy and informal counseling and guidance to the client and family. The treatment program was designed for a 6-month stay, which was felt to be the minimum time required for treatment in order to achieve any degree of success. Unfortunately, as will be see in a later section, this remains an empirical question.

Program Staging

An additional decision was made to employ staging of program components in an attempt both to combat denial and to enable gradual, progressive involvement in abuse and dependency treatment. The staging approach first involved the client in community meetings to establish relationships with the other clients and learn that others have had problems controlling drug and alcohol use. This was followed by participation in the education component, consisting of the core lectures regarding alcohol and drug abuse and dependency and the 12 steps. Finally, the group and individual counseling were added to the other components. This method also maintained program flexibility in providing services to clients with varying needs for the different program components. Each decision to add an additional component for a specific client was made with the treatment team.

Staff Development

Staff were selected for the program from applicants within a residential postacute rehabilitation facility. A staff training program was developed that consisted of approximately 20 hours of training broken into 1- or 2-hour modules, each covering a specific topic. The training was experiential as well as didactic, with tests administered before and after. The training program consisted of the modules shown in Table 1. As can be seen in this table, the training series provided education, personal value clarification, and experience in several treatment program components. It is felt that all three of these domains are important in a staff development program of this sort. It was found, for example, that the staff had widely diverse levels of education, values, and attitudes regarding chemical abuse and dependency. This diversity was felt to be a potential impediment to continuity and effectiveness, making consistency of treatment across all staff members impossible to achieve.

Following completion of the training, the staff began building the treatment schedule and program content. Fortunately some staff had previous experience in chemical dependency rehabilitation, and one individual was a certified substance abuse counselor with several years of experience in program development as well as in clinical treatment. Having completed this process, the program began accepting clients.

Table 2 shows the data collected on the pretreatment characteristics of the seven clients (six males, one female) treated in the program to date. It can be seen that these clients fit the usual demographic profile of persons with head injury with respect to age and education.[9] Of those for whom length of coma was known, it appears that they averaged almost 3 weeks, indicating very severe head injury. Although three of the seven clients came into the program within 6 months of their injuries, four were more than 1 year postinjury. All clients used alcohol, and most used marijuana as well. Two clients were polydrug abusers. At the time of their injuries, three clients were living at home and attending high school. The other four clients were living independently and were competitively employed, three in skilled employment and one at the professional level.

Table 1.
Staff Training Curriculum

Topic	Content
RELATE program philosophy	Program background, organization, and content
Alcoholism review and pretest	Literature review, value clarification, attitudes
Alcoholism as a disease process	Symptoms of addiction and dependency and rehabilitation
Core lectures - stages of recovery, 12-step process, and AA meeting	Overview of the AA-NA model
Denial and coping, problems, and treatment	Description of denial and other coping mechanisms and treatment approaches
Leisure counseling in abuse and dependency	Use of leisure time in abuse and dependency, structuring, and counseling
Wellness and addiction	Wellness, stress, and depression in abuse and dependency: signs, symptoms, and treatment
Spirituality in recovery	Development of personal definition and concept of spirituality, role and function in abuse, and dependency rehabilitation
Sample community meeting	Participation in and practice leading a community meeting with RELATE clients
Addiction to prescription medication	Psychopharmacology, addiction, and rehabilitation
Codependency and enabling processes	Psychodynamics of these processes; working with families
Behavioral intervention and environmental management	Techniques for behavioral and environmental structure

Diagnostic Severity

The summary data in Table 2 show that the clients treated in the program not only were severely injured but also had long histories of chemical abuse or dependency. All clients for whom the information was available had ingested alcohol or drugs at the time of their injuries. Furthermore, 86% or six of the seven clients had been treated for alcohol or drug problems previous to their head injury. Four of the seven (57%) had participated in AA or NA prior to the head injury. Five of the seven (71%) had histories of arrest or truancy prior to injury. In addition, 43% reported job loss due to chemical use. Five of the seven had families with histories of chemical abuse or dependency, and five clients began their abuse or dependency before the age of 15. This is clearly a population whose diagnoses in both categories, head injury and chemical abuse or dependency, was severe.

Table 2.
Client History on Admission

	Client Number								
History	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**Mean**	**SD**
Age at injury	18	17	35	16	30	37	34	26.7	9.3
Education	10	12	12	10	10	13	12	11	1.2
Time since injury (months)	12	120	3	4	15	42	6	28.8	42.3
Length of coma (days)	14	19	4	35	U	U	U	18	12.9
Age began using	13	13	25	13	9	19	14	15	5.2
Substance	Poly	ETOH	ETOH	Mari	Poly	ETOH	Poly	ETOH	
Age entering RELATE	19	27	36	16	32	41	34	29.2	9.1
Family history (abuse or dependency)	Yes	No	No	Yes	Yes	Yes	Yes	71%	
Chemicals in injury	Yes	Yes	Yes	Yes	Yes	U	Yes	100%	
Job loss	Yes	Yes	No	N/A	No	No	Yes	50%	
Participation in AA	No	Yes	No	No	Yes	Yes	Yes	57%	
Previous drug rehabilitation	Yes	Yes	Yes	No	Yes	Yes	Yes	86%	
Arrests or truancy	Yes	Yes	No	Yes	Yes	No	Yes	71%	

U, unknown; Poly, polydrug; ETOH, alcohol; Mari, marijuana.

Referral And Admission Pattern

In the first 9 months of operation, a total of 25 referrals to the program were received. Of these, 15 clients (60%) were not admitted for lack of financial resources, 7 clients (28%) were admitted, and 3 clients (12%) decided not to enter the program. Of the 18 clients who were clinically approved but not admitted, 15 (83%) were not accepted because of inadequate funding. The other 3 clients (17%) decided not to enter the program because of the distance from their homes. A large number of inquiries were made to the program regarding client referrals; however, few of these inquiries resulted in referrals, primarily as a result of lack of funding.

RELATE's experience has been that third-party insurers were generally unwilling to fund treatment for these clients and, as shown in the attrition data, unwilling also to allow clients to remain in the program for the requested and intended 6-month treatment period. Approximately 30 referrals for services were made to the program, from which the 7 clients described in Table 2 were admitted. Reasons for nonacceptance of referrals were clinical ineligibility (approximately one third) and lack of funding resources (approximately two thirds), despite a nearly universal report from the insurance case managers and social worker, who were the primary referral sources, that the program was greatly needed. Although this program provided a relatively small data set, it is believed to be representative of the general situation within this population. Clearly, in order for this and other innovative rehabilitation programs to survive, greater funding support is necessary from the insurance industry and other sources.

Examination of the sources of referrals to this program yields interesting information. Of the 7 clients admitted to the program, 1 came from an inpatient chemical dependency treatment program, 1 came from home, 1 from jail, and 4 from other rehabilitation programs. These sources, together with psychiatric hospitals, were also the primary referral sources for clients not admitted. Referral sources frequently indicated that the client was not being served appropriately in the current setting and, in most instances, there were significant behavior problems. Referral sources also frequently indicated that the RELATE program was the final opportunity for these clients to receive services.

Client Outcomes

Despite the small sample size, two types of outcome can be described, as well as some preliminary indications regarding the importance of various client and program attributes that may be relevant. Short-term outcomes are defined as 90 to 180 days following discharge. Long-term prognosis was defined as staff consensus regarding probability of remaining chemical-free. Table 3 shows that staff prognosis proved to be relatively unreliable as an estimate of client outcome. As can be seen, all clients discharged from the program received recommendations for additional rehabilitation or psychiatric treatment. In those cases where the recommendations were followed, clients appeared to remain chemical-free on follow-up. In those cases in which the recommendations were not followed, clients did not remain free of chemical abuse or dependency. These preliminary findings, when combined with the inability to keep clients in treatment for the 6-month period, probably account for the reasons these clients were for the most part not successful in maintaining sobriety.

In addition to the outcomes described in the individual case studies below, one client left the program against advice and at last report was living with his brother, competitively employed but using drugs. Another client went home with her parents but was physically abusive to them, and placement in a neurobehavioral facility was underway. Still another client went home to his family but, because of premorbid obsessive-compulsive behavior, was sent to a psychiatric facility. Attempted elopement from this facility resulted in placement in a neurobehavioral rehabilitation facility. Attempts to contact the remaining client were unsuccessful, so the outcome for that individual is unknown.

Variables

Overall, there does not appear to be any relationship between time since injury on either short-term outcome or positive prognosis for long-term adaption. This is an interesting finding, because some studies have shown that early intervention produces better outcomes or substantial cost savings.[10,11] The clients in this sample had an average of 11.5 years of abuse or dependency (SD-7.9) prior to their injuries, but even this variable does not appear to be related to successful prognosis.

Table 3.

Client Characteristics at discharge

Characteristics	Client Number						
	1	2	3	4	5	6	7
Time in RELATE (months)	1.5	5	1	2	3	7.5	3
RELATE/TBI (%)	90/10	85/15	25/75	50/50	66/33	33/66	50/50
Staff prognosis at discharge	No	Yes	Yes	No	Yes	No	Yes
Family participation in treatment or aftercare	No	No	No	No	Yes	No	Yes
Additional treatment recommended at discharge (psychiatric rehabilitation)	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Recommendations followed	No	Yes	Yes	No	No	No	Yes
Sober at follow-up	No	Yes	U	Yes	No	No	Yes

U, unknown

Severity of injury, as measured by length of coma, for those clients for whom this information was known also did not account for successful short-term outcome or long-term prognosis. Furthermore, neither family history of abuse or dependency nor family involvement in treatment and aftercare appear to relate to short-term outcome or prognosis for success. Length of stay in the program did not appear to relate to the successful outcome. However, none of the clients reached the 6 month length of stay intended for the program. It seems that other interpersonal or intrapersonal variables, such as participation in aftercare support groups or even individual willingness to change, may play a much more important role in successful outcome, at least in the short-term. Of course, long-term prognosis is not the best measure of outcome, and these predictions may be flawed. The small sample size makes generalization to larger populations impossible.

Length Of Stay

Length of stay was felt to be an important variable in this program. The extent of cognitive and behavioral impairments in this population made the traditional 28-day program insufficient to meet the treatment needs of this population. Length of stay must be sufficient to enable dual diagnosis clients to acquire the necessary reinforcement history for sobriety and the chemical dependency awareness that will enable lasting changes to occur.

The average length of stay in the program was 3.38 months. Three of the seven clients were discharged owing to discontinuation of funding. One client was discharged against advice of the treatment team, and one client was discharged by the team for lack of participation. The high rate of attrition from this program (five of seven clients), is obviously an important problem, and termination of reimbursement by insurance carriers is by far the greatest contributor to attrition. While it is believed that had more clients remained in the program for the full 6 months the outcomes would have been more successful, nevertheless, this remains an empirical question.

Case Studies

Client AB

Client AB was a 32-year-old divorced male who received a TBI in May 1987 in a motor vehicle accident. He was intoxicated at the time of the accident. He was admitted to the RELATE program approximately 18 months after his injury, following repeated incarceration and charges of public intoxication. AB had participated in a 28-day chemical dependency treatment program, but the success of this treatment was short-lived. He was admitted to the RELATE program as an alternative to jail. His drugs of choice were alcohol and marijuana.

On admission, AB's primary functional deficits included severely impaired expressive speech and writing and behavioral acting out. Length of stay for this client was 3 months, after which he was discharged as a result of termination of insurance funding. AB's rehabilitation program consisted of approximately 33% intensive brain injury rehabilitation and 66% chemical dependency rehabilitation, measured in terms of number of units of services delivered. AB's treatment consisted of speech therapy, psychological counseling, art therapy, recreation therapy, occupational therapy, and drug and alcohol education and counseling. To meet AB's severe expressive communication deficits, all therapies were provided verbally and presented in a manner that he could comprehend. He was encouraged to gesture or draw to communicate in therapy sessions. The "Big Book"[6] (the major text of AA), was obtained on audio tape and given to him for personal use. (The Big Book consists of a history of the development of AA, a description and rationale for the 12-step model of sobriety, and a number of case histories. It is used by AA groups throughout the United States as the standard reference for the AA treatment model.) He participated well in chemical dependency rehabilitation, completed his assignments, and attended AA meetings regularly, the latter with the supervision of the RELATE staff member to assist him with communication in these groups and to prompt appropriate behavior.

AB's response to the RELATE program was positive, and he was able to make a strong and seemingly genuine commitment to discontinue his use of alcohol. However, he had no inclination to stop using marijuana. He was particularly enthusiastic regarding the art and communication therapies. In art he discovered a new means of self-expression, and in speech therapy he improved in communication skills. On one occasion, AB and another client left the program and drank several beers. This was treated as a relapse in his abstinence program, and AB renewed his commitment to sobriety with the proviso that further incidents would result in his termination from the program. Unfortunately, AB's premature discharge did not enable him to complete the program or to internalize fully his commitment to sobriety.

Following his discharge from the RELATE program, AB returned home and began seeking vocational rehabilitation (VR) services. While waiting to achieve the 6-months sobriety requirement, he was not attending AA meetings, and he began drinking. Because VR eligibility requires a 6-month history of abstinence, AB became ineligible for assistance from this agency. He did obtain sheltered employment with VR assistance, but this lasted only 2 weeks following two incidents of walking off the job. He was eventually arrested and jailed for public intoxication. This was a keenly felt disappointment for the rehabilitation staff, because it was believed that had AB received additional treatment in the RELATE program, he could have remained sober.

Client BC

Client BC was a 27-year-old single man who was intoxicated at the time of receiving a TBI in an automobile accident in August 1978. During the 11 years between his injury and his admission to the RELATE program, BC had several admissions to psychiatric treatment programs, including six consecutive admissions to one hospital. He had one admission to a chemical dependency treatment program, also. Although the treatment teams in these facilities were aware of his head injury, BC had been misdiagnosed for some time. Neither psychiatric nor pharmacologic treatment had been effective for him. He had lost a number of jobs after short periods due to alcoholism.

Cognitively, BC was fairly high level, with only minor deficits of "executive functions," which were not barriers to competitive employment or independent living. A more significant observation was that BC demonstrated inconsistent commitment to sobriety and required considerable support and reinforcement from others.

BC's participation in the RELATE program consisted of 85% chemical dependency rehabilitation and 15% brain injury rehabilitation, including psychological counseling, occupational therapy, speech and cognitive therapy, art therapy, and group alcohol and drug education and counseling. Since his cognitive deficits were comparatively mild, very few adaptations to the basic AA model were made in his rehabilitation program, other than frequent review of material and assistance with completion of written assignments. BC's response to the rehabilitation process constituted a definable pattern of a "honeymoon" period of participation and compliance; active resistance to treatment, leading to elopement; considerable progress in cognitive skills and emotional coping skills; and, toward the end of his program, refusal to participate. BC requested an early discharge in order to return home and become more involved with VR services in his home community. This request followed shortly after an elopement during which he drank several beers. Upon his return from the elopement, BC was requested to sign a behavioral contract to prevent further elopements. It was at this point that he decided to return home.

Following his discharge from the RELATE program, BC attended the VR planning meeting with his family to develop his plan of service. However, during the interim he began using alcohol and was subsequently placed in a chemical dependency rehabilitation program, which he completed successfully. He recently informed the staff that he had been sober for 7 months and was involved in a vocational training program in welding.

Client CD

Client CD was a 34-year-old single man injured in September 1988 in a police chase. He was intoxicated at the time. CD had an extensive history of drug use and sales. He had participated in a chemical dependency treatment program prior to his injury. CD was admitted to the RELATE program from a postacute rehabilitation setting, and to the postacute setting from an acute rehabilitation hospital setting. He had severe behavioral, cognitive, and physical impairments at the time of admission.

Because of CD's behavioral deficits, he did not begin participation in the RELATE program until 3 months after his admission to the postacute facility. His program consisted of approximately 50% brain injury rehabilitation and 50% chemical dependency rehabilitation. Services included speech therapy, physical therapy, occupational therapy, psychological counseling, recreational therapy, group alcohol and drug education and counseling, intensive behavioral rehabilitation, and social skills training. CD's family also participated in counseling. Other than gradual participation in the program and slow, repetitive presentation of educational information, CD required few adaptations. His ability to read was adequate for the assignments, and assistance with writing tasks was provided.

CD's participation in the program was very positive. He struggled with and overcame his dependence on chemicals and achieved a full year of sobriety. He was discharged for further treatment to a postacute rehabilitation facility closer to his home, to enable increased family involvement and therapy. At the time, no wheelchair-accessible NA meeting was available in his home community, which compromised aftercare treatment. Follow-up attempts to contact CD and his family have been unsuccessful, so longer-term outcome information is unavailable. However, successful abstinence seems unlikely.

Aftercare

As a result, in part, of experiences with these clients, the program focuses particular emphases on discharge planning and aftercare. This process involves several components; development of a "disaster plan," development of an appropriate discharge placement, development of a support system in the discharge environment (AA or NA meetings and sponsors, family, and friends), and education of the client's support system.

Disaster Plan

All clients developed a plan of action to use when a need was experienced to use chemicals. The plan usually involved the use of coping and relaxation skills learned and practiced in the RELATE program, self-instructions, and a list of individuals they could call on for support or assistance (such as an AA or NA sponsor, family, a friend, or a counselor). The clients then presented their plans to their treatment team, other clients, and families to obtain reinforcement and support.

Discharge Placement

Discharge planning included several considerations; ability and motivation to attend AA or NA meetings, extent of external structure required to maintain freedom from chemicals, ability to make support contacts independently, and support needed to ensure use of the disaster plan when needed. These elements were considered the minimum requirements for an individual to remain free from the use of chemicals. Other considerations were the friends of the individual and their potential negative influence, the presence and extent of abuse or dependency patterns in the client's family, and employment or work activities that would support the sobriety of the client.

Discharge Environment Support System

This is considered a crucial aspect of successful discharge planning within the RELATE program. Prior to discharge, the client and family were interviewed to discover various support resources in the home community. Continuing involvement in AA or NA also is considered crucial. Discharge planning recommendations included the need to attend 90 meetings in the first 90 days following discharge, a component usually included in traditional abuse and dependency rehabilitation programs. The client and family are assisted in determining the dates, times, and locations of meetings, in finding possible sponsors, and in ensuring adequate transportation. Contacts with VR counselors and chemical-avoidant social groups, including local head injury association support groups, were also developed for the client.

Our experience in the RELATE program indicates that both professionals in rehabilitation and lay people working with individuals who are both brain injured and chemically dependent or abusive experience considerable frustration, codependency, and enabling. Education therefore becomes an important component of successful discharge planning. Individuals central to the client were invited to tour the RELATE program, and written information was provided to all those who would be working with him or her. Telephone support was available at all times. Follow-up contacts were initiated six times during the five years after discharge.

The National Head Injury Foundation revealed in its 1988 White Paper report that the relationship between chemical use or abuse and TBI is highly significant and that special treatment is required by this dual diagnosis population.[1] The RELATE program represents an attempt to develop a successful program model for serving these individuals. Based on approximately 9 months of operation, several conclusions and recommendations have emerged.

The clients with the greatest potential for long-term success appear to be those with the most recent histories of both chemical abuse or dependency and brain injury, those with the least impairment of higher level cognitive functions, and those who may be more amenable to a commitment to change to a chemical-free lifestyle. The commitment to change is extremely important, and as a predictor of successful outcome. Experience in this program has shown that this commitment must be addressed early in the treatment process and should remain a point of considerable emphasis throughout the program.

Our experience thus far also indicates that the most important predicator of successful outcome is the presence of community based support systems. Included here are not only AA and NA support groups, but community social and vocational support systems. Several clients in this program were not able to receive VR assistance on discharge, and this contributed to a return to a lifestyle of substance abuse. In addition, clients who return to a social system of friends who are chemically dependent or abusive have a much greater probability of relapse than those who have access to a chemical-free social system. Discharge planning efforts must ensure that these support systems are in place prior to discharge.

The program must be sufficiently flexible in structure to provide effective treatment for clients with differing cognitive abilities. Furthermore, the relative balance between brain injury and chemical dependency rehabilitation must also be flexible and able to change as the client makes progress in either area.

Family involvement is both a significant problem and a crucial element for successful long-term functioning. It is a problem because of the number of families with histories of chemical abuse and dependency. However, families are also the most salient force in the lives of most of our clients, and are thus capable of the greatest influence on the client. Therefore, family education and counseling are extremely important. Ongoing family counseling and guidance after discharge of the client also are important.

RELATE strongly believes that clients must have at least 6 months of funding for this type of rehabilitation to provide the intensity and continuity of services that will maximize the probability of long-term success. This period is the minimum necessary, particularly for those clients with more severe cognitive limitations. It is necessary also to ensure at least 6 months of sobriety prior to returning home. Many VR counselors require this period of sobriety for eligibility for state VR services.

Successful treatment requires group, individual, and peer counseling and support. A balance must be maintained between the extent of reinforcement and support and the confrontation with inappropriate attitudes and behaviors on the part of the client.

The AA-NA 12-step model appears appropriate for brain-injured clients, given sufficient repetition and slow enough pacing of training to ensure cognitive comprehension and processing. Furthermore, this established support group system is widely available in the United States, facilitating aftercare programming. Moreover, since this will be the primary ongoing support mechanism postdischarge, the client is better served by introducing this model early in the rehabilitation process.

It is apparent from RELATE's experience thus far that inpatient rehabilitation treatment for the dually diagnosed brain-injured and chemically abusive or dependent client is necessary to ensure successful, long-term reintegration into the community. Additional experience will refine this program and increase its effectiveness. Considerable effort must be expended toward educating the insurance industry regarding the need and potential for success of this type of program if adequate funding support for this population is to be ensured.

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A Look at Alcohol and Other Drug Abuse Prevention and ...... Traumatic Brain Injury

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Traumatic brain injury (TBI) refers to damage to the brain caused by external mechanical forces applied to the head. The traumatic brain injury is acquired suddenly in the course of normal development. It typically results in brain damage which is diffuse or widespread; it is not usually confined to one area of the brain. Thus, impairments are multiple and many aspects of life are changed.

Someone receives a traumatic brain injury every 15 seconds in the United States. Over 2 million injuries occur per year with 500,000 severe enough to require hospital admission. Between 75,000 and 100,000 people die each year from a traumatic brain injury, which is also the leading killer and cause for disability in children and young adults. The economic costs alone approach $25 billion per year, and astronomical medical and legal bills often leave families in financial ruin.

Among those who survive, 90,000 people will be severely and permanently disabled. They will experience deficits in physical, psychosocial, intellectual, cognitive, vocational, educational, recreational, and independent living skills. These deficits will vary in intensity over time, and will interact in ways unpredictable and unique. These interactions require extremely complex management and rehabilitation methods.

The Implications Of Alcohol And Other Drug Use

Alcohol abuse has been associated with TBI in over half of all occurrences. It appears to be related in many cases with lifestyles where alcohol and other drug abuse and risk taking are common (Sparadeo, et al., 1990). If the disability is a direct result of alcohol or other drug use, or if it predates the disability, the chances are greater that the problems will continue following rehabilitation. The continued abuse of alcohol and other drugs can negate attempts at physical, social, and cognitive rehabilitation.

Specialized alcohol and other drug abuse treatment often is necessary for people with traumatic brain injury. TBI's can include lasting memory and cognitive difficulties, and alcohol and other drug abuse treatment needs should be addressed by taking learning styles and capacities into consideration. Medical care for TBI is costly, and it is not uncommon to exhaust financial resources before the person can access appropriate alcohol and other drug abuse treatment.

Alcohol and other drug abuse prevention might best be approached by emphasizing the effects of alcohol and other drug use upon the damaged brain and a person's recovery from TBI. For example, the following points might be emphasized in the discussion with a person with TBI:

- The disinhibiting effects of alcohol are not helpful when disinhibition itself is a social problem for many persons with TBI.
- The depressant effects of alcohol and many other drugs are not helpful when proneness to major reactive depressive episodes are so common among persons recovering from TBI.
- The effects of alcohol and other drugs may interfere with medications designed to prevalent seizure episodes. They also may lower the seizure threshold.
- It is highly undesirable to exacerbate deficits in planning, verbal fluency, motor control, concentration, attention, memory, and information procession speed, which are already problems in recovering from TBI.

Suggestions To Improve Positive Interactions

People with TBI may digress or change course during a conversation. Redirect them using appropriate cues and reinforcers.

Teach prevention skills to the person with TBI in more than one setting to maximize generalization. Focus on a specific prevention goal.

Be redundant. Never assume understanding or memory from a previous session. Always repeat the purpose, duration, and guidelines for each meeting. Summarize previous progress and then restate where the previous meeting left off.

It must be understood that because the consequences of TBI are so psychologically overwhelming, most persons experience pervasive denial. This is perfectly normal. The timing and method of confrontation and deficits, including alcohol and other drug problems, should be carefully coordinated with the interdisciplinary TBI treatment team and case manager.

Present educational points in the most effective cognitive and sensory mode. This information is best obtained from a TBI team member known as the Cognitive Specialist.

All interventions should be directive in nature, short term, goal directed, and behaviorally anchored.

Severe brain injuries are typically so devastating to the family system that many family members "leave the field" when they come to appreciate what has occurred. Social isolation is common for people with TBI. The family system must be assessed and reassessed as it will fluctuate markedly in the first four years following TBI.

Accentuate positive gains using frequent social praise.

Myths and Facts

MYTH: *Most people with a very severe TBI will likely die.*

FACT: Because of advances over the last two decades in emergency room medicine, neurosurgical techniques, and pharmacological agents, the survival rate for people with severe TBI has quadrupled to nearly 60%. Most are young adult males who will live a full lifespan.

MYTH: *Brain damage is permanent and irreversible. Life after TBI is not worth living.*

FACT: There is a period of spontaneous neurological recovery of about two years in which significant improvements occur. These can be sometimes augmented by extensive and expensive rehabilitation methods. Some people with severe TBI will eventually live independently and work competitively with supports, but rarely at the level of functioning they enjoyed prior to injury.

MYTH: *People with TBI are volatile, aggressive, and unpredictable.*

FACT: Almost all people who have experienced severe TBI pass through a phase of agitation during their recovery. This is normal and must not be confused with a permanent psychiatric condition. Behavioral problems that do linger for a minority of persons with TBI will likely include confusion, disinhibition, and/or reservation as opposed to aggression.

MYTH: *Most TBI's occur among people who were drinking and driving.*

FACT: About two-thirds of TBI's involve motor vehicle accidents. Half of the accidents which resulted in TBI are alcohol-related. Even in these circumstances, the people incurring TBI were often passengers or not intoxicated themselves. Falls, work-related accidents, sports-related injuries, and firearms account for many head injuries.

MYTH: *People with TBI experience dramatic losses of intellectual functioning.*

FACT: There is usually some loss of intellectual functioning, but this can be confused with more specific cognitive deficits such as problems in attention/ concentration, short-term memory, or the speed of information processing. These are often the most significant impediments to long-term recovery.

MYTH: *The point of impact and force of a TBI tells us a great deal about its consequences.*

FACT: Most brain injuries are diffuse (affecting the whole brain and brain stem) and are not localized. The combinations and permutations of damage to over 10 billion interdependent nerve fibers are almost infinite, as are the manifestations of TBI.

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This information was developed as part of a set of materials on alcohol and other drug abuse prevention and disability. Other documents on specific topics are available upon request. Produced by VSA Educational Services, Resource Center on Substance Abuse Prevention and Disability. Funded by the U.S. Department of Health and Human Services, Office for Substance Abuse Prevention, Division of Communication Programs.

Section J

Sexuality and Brain Injury

Sexuality and Brain Injury

Goal

Significant sexual dysfunction is not uncommon after traumatic brain injury (TBI) and affects not only the person who sustained the trauma, but also his/her partner, family and community. Sexuality is an integrative function, requiring the integration of physical, cognitive and psychosocial behaviors in order to be expressed. The person with TBI could experience difficulty in any, or all, of these behavior categories as they pertain to sexuality. Family members and service providers often experience barriers that prevent them from accepting that a person with TBI still is a sexual being. This section contains information regarding the physical, neuropsychological, psychosocial and legal aspects of sexuality and TBI. It is designed to encourage presentations of a balanced and comprehensive view of sexuality issues after brain injury.

Objectives

1. To provide accurate information on common and uncommon problems in sexuality after brain injury, their relative frequency, evaluation and management approaches.

2. To promote a normalizing and empowering approach to sexual concerns of people with brain injuries.

3. To increase awareness of sexual concerns, comfort in eliciting and providing information about sexuality, and motivation of professionals to consistently do so in acute medical, rehabilitation and community settings.

4. To improve the quality of services provided to survivors and families, particularly to women with injuries, and reduce sexual discrimination in rehabilitation practice.

Selected Resources for Sexuality and Brain Injury

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A Fool Uttereth All His Mind. Billy Golfus. National Disability Awareness Project/In-Beat, Inc,
513 Ontario Street, SE, Minneapolis, MN 55414
(612) 331-1130.
Fax (612) 379-2760. Work in Progress, "trailer" video available.

Choices. Mercury Productions, 17 West 45th Street, New York, NY, 10036.
(212) 869-4073.
$60 rental, $300 purchase.

Here. Cheryl Marie Wade, 1613 5th Street, Berkeley, CA 94710-1714. $25.00 individual, $15.00 low income, $35.00 institute.

People

Ed Roberts
World Institute on Disability
510 16th Street
Oakland, CA 94612
(415) 763-4109

Sexuality and Intimacy Issues in Community Integration of Persons with TBI: A Slide Narrative

by

Vikki Stefans, MD, MS

This script was designed to be used with the slide presentation which is located in the Appendix (pages M.33 - M.55) of this manual. The reader is encouraged to use these illustrations for preparing slides or transparencies and sharing this information with a larger audience.

Slides 1 and 2

Sexuality and intimacy following traumatic brain injury involve many interlocking and complex medical, neuropsychological, and societal issues and concerns. There is a great deal of head injury literature, most devoted to management of inappropriate or hypersexual behaviors. We must draw on the experiences of families and survivors and some literature from other fields, including general disability and sexuality to create a balanced picture of real human needs in this arena.

Slide 3

Medical issues directly related to brain trauma involve the neuroendocrine system. Pituitary and hypothalamic dysfunction of a subtle nature are probably more common than realized, and other dysfunctions must be diagnosed and treated to prevent serious complications such as electrolyte imbalance, hypothyroidism or inadequate adrenal function under stress. Although there are case reports of precocious puberty in children with brain injury, these conditions are associated with decreased sexual functioning and occasionally even infertility. Fertility is usually unaffected by brain injury in either sex, in contrast to spinal cord injury in males.

Slide 3a

Medication side effects are more common than prescribing professionals would like to believe, and may be overlooked if cognitive symptoms such as fatigue and confusion are ascribed solely to the brain injury itself. For example, survivors may report surprising improvements in well-being or cognition when anticholinergics (such as Ditropan, Coxybutinim for bladder spasms) or other sedating medications are decreased or discontinued. Nearly all antihypertensive medications can directly reduce sex drive or sexual performance functions or both. Effects of medication during pregnancy should also be considered for all females of child bearing age.

Slide 4

Particularly for women on anticonvulsants, the effect of these on pregnancy as well as sexuality should be considered. This summary chart is drawn from presentations by Selwyn Lloyd McPherson, MD, of the Epilepsy Diagnostic and Treatment Center in Akron, Ohio. Use of anticonvulsants is not always contraindicated during pregnancy; Dilantin (phenytoin) and Depakene (valproic acid) slightly increase the risks of congenital malformation, but the greatest risk during pregnancy is that of uncontrolled seizures. These issues must be carefully considered by each woman and her physician.

Slide 5

Commonly described neuropsychological dysfunctions that may affect sexuality and intimacy include disinhibition, impulsivity, and insatiable sex drive - which is worsened by memory impairment. These behaviors are seriously problematic for families and society and demand corrective attention.

Slide 6

However, it should be noted that these types of behaviors are seen only one to ten percent of the time in actual surveys, and that the majority of survivors experience reduction in sexual drive, function, and/or activity.

Slides 7 and 7a

This may be related to neuropsychological problems as well as medical ones. With or without traumatic brain injury, factors such as stress, anxiety, depression, fatigue, or communication problems can interfere with sexual relationships. These factors can certainly be related to recent brain injury and its general or specific sequelae.

Slide 8

Appropriate response to human sexuality and need for intimacy begins with taking a sexual history at the beginning of the rehabilitation process. Even if the individual is "not ready" to open up about sexual issues, it at least conveys permission to ask questions or exchange more information at a later time. Pre-injury behavior, values and 'norms' should be understood and used as a basis for dealing with post-injury function. Diminished function must be inquired about to be detected.

Slide 9

This is an excerpt from "The Spouse's Perspective" by Tom Medlor and may be simply shown or read without comment for best effect and impact.

Slide 10

Hypersexual or inappropriate sexual behaviors are not only disruptive in the rehabilitation environment and process, but also in the workplace. These examples are taken from the HDI Professional Series booklet Hiring the Head-Injured: What to Expect, except the third example, which was directly observed in an academic medical office where none of the employees had any history of brain injury.

Slides 11 and 11a

The reputation for these behaviors may be a partly misperceived one, due to the pre-injury characteristics of those most likely to sustain severe traumatic brain injury (TBI). Males, ages 15-35, have the greatest incidence of brain injury, especially those of low socio-economic status. These persons tend to be psychologically vulnerable and immature, and prone to compensatory risk-taking behaviors, "low responsibility level", and a higher incidence of alcohol and other substance abuse.

Slide 12

But whether pre-morbid, pre-morbid and exacerbated by TBI, or caused by TBI, these behaviors must be addressed. First, as in handling any behavior issue, one must carefully identify, analyze and correct any environmental or management factors which may be creating or exacerbating the problem. Those working with individuals who survive TBI must examine their attitude towards sexuality and sexual expression / sexual intimacy and relationships of people with disabilities. Avoidance of automatic controlling and restricting of all behaviors, such as placing people in "time-out" for any touching of other people, or restraining to prevent masturbation, is essential from a patient rights standpoint and also because the negative attention may in fact reinforce and perpetuate increased behaviors. Privacy for appropriate sexual outlets should be provided. Positive approaches such as modeling and peer counseling should be the next steps considered.

Slide 13

Supervision and restriction are necessary for certain behaviors that infringe on the rights of other persons or directly violate public laws and standards of decency.

Slide 14

With any needed modifications for cognitive level, one general model of intervention that can be applied for TBI-related concerns is the "PLISSIT" model. The first step is to give permission to talk about and explore the issues of sexuality and intimacy. The second step is to provide basic information in response to questions or expressed needs. The next step is to provide specific suggestions, such as the now traditional methods of getting around physical limitations such as those imposed by spinal cord injury, back pain or arthritis. Finally, intensive therapy requiring expert referral may be indicated.

Slide 15

Reframing deficits such as anomia or abulia (lack of independent initiative) for a spouse, reassuring that problems are common but may be resolved or that sexual activity after disability is neither harmful nor inappropriate may be essential.

Slide 16

Careful consideration of medical, physical, neuropsychological, social and environmental factors and treatment or management is required if significant problems persist.

Slide 17

Another tool which has been adapted for use after TBI is Sexual Assessment Planning, as described by Dr. Kenneth Lefebre. It is meant to help address readiness to intervene directly in sexual adjustment issues, scoring areas of relationship with professionals, cognition, motivation, and prior psychosocial history. It should not be used rigidly to exclude consideration of sexual or intimacy issues, but to gain an understanding of a person's present perspective before more intensive work in the area is undertaken.

Slide 18

Sexuality/intimacy is only one of the milestones or cornerstones of adult functional expectations. Adulthood implies autonomy and ability. Imposing limitations to that autonomy should not be taken lightly, and if this must be done, it should be done in the least restrictive manner possible. Persons with cognitive disabilities may indeed be at risk of "being taken advantage of" but can also make appropriate decisions based on their own values and receive training on aspects of decision-making in regard to sexual activity.

Slide 19

Persons who are non-verbal are at particular risk for sexual abuse, and subtle symptoms should trigger appropriate evaluation and intervention. Most professionals are actually "mandated reporters" of abuse in most states, especially if the suspected abuse involves a minor and may report directly to outside agencies even if approval of supervisors cannot be obtained.

The most common issue is that of failure to provide for the privacy and dignity of individuals with disabilities possibly related to failure to perceive them as fully sexual beings with human needs for modesty and respect.

There is evidence in both TBI and also stroke literature that women are discriminated against in the rehabilitation process just as they have been in the larger society. They are seen as less likely to resume adult roles or achieve the adult milestones.

Slide 20

"Their" issues receive considerably less attention in practice as well as in the literature.

The following sample forms are provided as examples of procedures that may be used to obtain "Informed Consent" of a client or the client's guardian to provide education about sexuality issues that should be faced openly and concretely during the rehabilitation process.

(SAMPLE FORM)

Consent for Gynecological Care, Administration of Birth Control, Sex Education and Counseling, and Acknowledgement and Waiver with Respect to Sexual Contact, and Consequences Thereof

____ is a client of

____ (the "Center").

The undersigned hereby authorizes the Center including, without limitations, its rehabilitation services staff, to seek and authorize, upon reasonable notice to the undersigned, obstetrical and gynecological care, as the Center, including its rehabilitation services staff, in its sole discretion, deems necessary or appropriate, including but not limited to regular gynecological exams performed by an MD or Ob/Gyn Nurse Practitioner; blood tests and other tests for diagnosing sexually transmitted diseases; treatment of sexually transmitted diseases, including drug therapy; other routine gynecological procedures and tests; and prescription instruction, and administration of birth control drugs and devices, including but not limited to prescription and insertion of an Intrauterine Device (IUD).

The undersigned hereby acknowledges and understands the medical risks associated with birth control pills and intrauterine devices. In consideration of admission to the Center, the undersigned hereby holds the Center, its employees and agents harmless from any and all complications, including but not limited to pregnancy, experienced in association with prescription, administration, insertion, or use of birth control pills or the intrauterine device.

The undersigned hereby acknowledges that sex education classes and/or group and/or individual counseling are part of the Program at the Center. The Center's sex education classes and counseling will include, but are not limited to, such topics as: birth control, venereal and other sexually transmitted diseases, hygiene, pregnancy, intimacy, and gender identification. The undersigned hereby consents to the participation in such sex education classes and counseling provided by the Center.

The undersigned hereby acknowledges that the Center assumes no responsibility for clients engaging in voluntary sexual contact with others while residing at the Center with or without the Center's knowledge. The undersigned hereby acknowledges that such sexual contact may result in venereal and/or other sexually transmitted diseases and/or pregnancy. In consideration of admission to the Center, the undersigned hereby agrees to hold the Center, its employees and agents, harmless from any and all consequences or expenses of such sexual contact, including but not limited to medically curable, incurable or possible fatal venereal or other sexually transmitted diseases, sterility, pregnancy, abortion, complications of pregnancy, or birth of a child.

This signature remains valid until the date of graduation or discharge.

Client or Legal Guardian Date

Witness Date

(SAMPLE FORM)

Consent and Authorization for Sex Education and Counseling and Acknowledgement and Waiver with Respect to Sexual Contact and Consequences Thereof

____, is a client (the"Client")

of____ (the"Center").

The undersigned hereby acknowledges that sex education classes and/or group and/or individual counseling are part of the Program at the Center. The Center's sex education classes and counseling will include, but will not be limited to, such topics as: birth control, venereal and other sexually transmitted diseases, hygiene, pregnancy, intimacy, and gender identification. The undersigned hereby consents to participation in such sex education classes and counseling provided by the Center.

The undersigned hereby acknowledges that the Center assumes no responsibility for clients engaging in voluntary sexual contact with others while residing at the Center with or without the Center's knowledge. The undersigned hereby acknowledges that such sexual contact may result in venereal or other sexually transmitted diseases and/or pregnancy. In consideration of admission to the Center, the undersigned hereby agrees to hold the Center, its employees and agents, harmless from any and all medically curable, incurable or possible fatal venereal and /or other sexually transmitted diseases, sterility, pregnancy, abortion, complication of pregnancy, or birth of a child.

This signature remains valid until the date of graduation or discharge.

____

Client or Legal Guardian Date

____

Witness Date

Medications Can't Be Overlooked

by

James Wasco, MD

Reprinted with the permission from Headlines, January/February 1992, p. 24

The sexual complications of neurologic injury cover a vast spectrum - from hypersexuality, loss of inhibition, and exhibitionism to immature social skills, lack of interest, and depression. Physical handicaps and deformities impact sexual performance. Visual and speech problems interfere with communication and personal interaction. Cognitive impairments affect judgment.

Medication side effects may also contribute to the problem. The harmful effects of antihypertensives on sexual performance have been known for years. Now there is growing evidence that many of the traditional medications common to the rehabilitation setting may have the same consequences.

Rehabilitation professionals who do not see dysfunctional sexual conditions regularly may not be aware of the seriousness of this problem because the literature is still rather sparse in this area. And what few studies are available, have generally been done only on men. This unfortunate reality may reflect a double standard in sexual research - that somehow, sexual problems are more important to the male than the female. Or, it may be that investigators, who are mainly men, are simply uncomfortable in questioning female patients about their sexual experiences.

Nevertheless, review of the literature does identify several important problem areas.

Impotence. Most major classes of psychopharmacologic agents can be culprits, but in particular tricyclic antidepressants, monoamine oxidase inhibitors, lithium, and thioridazine. The issue is less clear for other major and minor tranquilizers.

Impaired or delayed ejaculation. The same drugs may be responsible. In fact, some physicians reportedly take advantage of this medication side effect when treating patients with premature ejaculation.

Hypersexuality. Levodopa and other adrenergic drugs can lead to increased libido and coital frequency, although there is a question of whether this is a direct drug effect or is merely secondary to increased motor activity.

Reduced libido. Sedatives and anticonvulsants may be responsible, but probably because of general CNS depression, rather than any direct effect on sexual function.

In most studies of these side effects, the clinical problems resolved when the offending medications were discontinued. The point can therefore be made that a drug history and current medication profile should be part of the screening process for any evaluation of sexual dysfunction. This is particularly important because many of our brain injury patients see several different physicians, all of whom may prescribe medications.

Compounding all of this is the difficulty in obtaining a clear understanding of preinjury sexual function. Memory disorders are certainly common in this patient population. Further, an individual's recollection of the past may be colored by mood. Depressed patients may tend to recall and focus only on poor sexual experiences, whereas manic patients may dwell on experiences that were more satisfying. The presence of a consistent partner can help to clarify the past history.

Contemporary rehabilitation programs must confront patient sexuality openly and directly, recognizing that persons with disabilities have sexual needs as well. If medical professionals do not bring up issues of sexual functioning, they may never be discussed at all. Patients often hesitate to volunteer information about these private areas of their lives.

Even though in recent years considerable advances have been made in the management of sexual dysfunction, there is overriding concern about the attention - or lack of it - that the medical and rehabilitation community often gives to sexual issues. One study found that physicians, nurses, and therapists initiated sexual histories less than 25 percent of the time in patient interviews. It may be because health professionals are not comfortable with the subject matter themselves. But even in otherwise well-informed medical communities, the assumption is sometimes wrongly made that sexuality is simply not an issue for physically- and cognitively-impaired individuals.

This silence can have serious consequences. In each of us, our sexuality is intimately related to our concept of ourselves. Without proper sexual awareness, we may lack the confidence to pursue social and personal relationships - indeed to interact with others in any meaningful way.

Section K

Neuropsychological Checklist

Neuropsychological Checklist

Goal

Neuropsychologists and Vocational Rehabilitation Counselors both have responsibility for helping persons with traumatic brain injury achieve full community integration. The success of the Vocational Rehabilitation Counselor in helping the person with TBI to have a positive vocational outcome is dependent to some extent upon the receipt of a sound neuropsychological report describing the individual's strengths and limitations in functional, vocationally-relevant terms. Neuropsychologists, on the other hand, rely on the expertise of the Vocational Rehabilitation Counselor to help the individual with TBI identify a feasible vocational objective, to assure that the individual obtains the necessary job skills, to work with employers on accommodations needed for job placement, and to provide job coaching and job placement assistance. The Checklist for Writing Neuropsychological Reports in Functional Terms for Vocational Rehabilitation is a procedure designed to facilitate communication between the two professional groups and to improve services to persons with TBI.

Objectives

1. To assist Neuropsychologists in writing functional reports when they are conducting assessments of persons with TBI who will be referred to, or who are receiving services from, a Vocational Rehabilitation Counselor.

2. To prepare Vocational Rehabilitation Counselors with a list of functionally relevant questions to ask Neuropsychologists when requesting a neuropsychological report.

Selected Resources for Neuropsychological Checklist

Articles and Books

Field JE, Field TF. The Classification of Jobs According to Worker Trait Factors. 3rd ed. Athens, GA: Elliot and Fitzpatrick; 1988.

Lezak M. Neuropsychological Assessment. 2nd ed.New York, NY: Oxford; 1983.

Spreen O, Strauss E. A Compendium of Neuropsychological Tests. New York, NY: Oxford; 1991.

U. S. Department of Labor. Handbook for Analyzing Jobs. Washington, DC: Government Printing Office; 1972.

Southwest Regional Brain Injury Rehabilitation and Prevention Center

Checklist for Writing Neuropsychological Reports in Functional Terms for Vocational Rehabilitation

by

Mary Ellen Young, PhD, Joyce Eisner-Leverenz, MS,
Linda Ewing-Cobbs, PhD, and Walter High, PhD

SECTION ONE: Cognitive Observations

A. Attention and Concentration

1. How long can client focus on a task?
   ☐ <5 min ☐ 5-30 min ☐ 30-60 min ☐ # of hours

2. Does client need breaks?
   ☐ usually ☐ sometimes ☐ rarely

3. Does client make impulsive errors?
   ☐ usually ☐ sometimes ☐ rarely

4. Is client distractable?
   ☐ usually ☐ sometimes ☐ rarely

   If usually or sometimes distractable, is the source of the distraction:
   ☐ external ☐ internal ☐ both?

5. Is client at increased risk in jobs involving specific hazardous conditions such as:

moving equipment	☐ yes	☐ no
electrical shock	☐ yes	☐ no
heights	☐ yes	☐ no
hazardous materials	☐ yes	☐ no
security/police duty	☐ yes	☐ no

B. Approach to Task and Problem Solving Skills

1. Can client use organized approach to tasks?
   ☐ usually ☐ sometimes ☐ rarely ☐ with prompts ☐ without prompts

2. Can client recognize errors?
   ☐ usually ☐ sometimes ☐ rarely ☐ with prompts ☐ without prompts

3. Can client correct errors?
   ☐ usually ☐ sometimes ☐ rarely ☐ with prompts ☐ without prompts

4. Can client accept and use feedback?
   ☐ usually ☐ sometimes ☐ rarely

5. Can client generate problem solving strategies?
   ☐ usually ☐ sometimes ☐ rarely ☐ with prompts ☐ without prompts

6. Can client change approach if ineffective?
   ☐ usually ☐ sometimes ☐ rarely ☐ with prompts ☐ without prompts

C. Memory

1. Does client have any problems remembering events that occurred or persons who were met prior to injury?
   ☐ yes ☐ no

If yes, please indicate whether client has problems remembering:

minutes before injury? ☐ yes ☐ no
hours before injury? ☐ yes ☐ no
day before injury? ☐ yes ☐ no
week before injury? ☐ yes ☐ no
month before injury? ☐ yes ☐ no

2. Does client have problems remembering current events or persons?

☐ yes ☐ no

If yes, please indicate whether client has problems remembering things that have happened:

in the last minute?	☐ yes	☐ no
in the last hour?	☐ yes	☐ no
in the last day?	☐ yes	☐ no
in the last week?	☐ yes	☐ no
in the last month?	☐ yes	☐ no

3. Does client have problems remembering one- or two-step directions?

☐ yes ☐ no

If yes, please indicate whether client has problems remembering:

for a minute?	☐ yes	☐ no
for an hour?	☐ yes	☐ no
for a day?	☐ yes	☐ no
for a week?	☐ yes	☐ no
for a month?	☐ yes	☐ no

4. Does client have problems remembering more complicated directions?

☐ yes ☐ no

If yes, please indicate whether client has problems remembering:

for a minute?	☐ yes	☐ no
for an hour?	☐ yes	☐ no
for a day?	☐ yes	☐ no
for a week?	☐ yes	☐ no
for a month?	☐ yes	☐ no

5. Are client's memory problems (check all that apply):
☐ global? ☐ visual? ☐ verbal?

6. Does client use memory aids?
☐ usually ☐ sometimes ☐ rarely ☐ with prompts ☐ without prompts

7. Does client ask for clarification and repetition of directions?
☐ usually ☐ sometimes ☐ rarely

8. Does client have more subtle problems remembering new information that impact the ability to do more complex jobs or tasks?
☐ yes ☐ no

D. Insight

1. Does client overestimate physical capacities?
☐ usually ☐ sometimes ☐ rarely

2. Does client overestimate memory abilities?
☐ usually ☐ sometimes ☐ rarely

3. Does client overestimate other cognitive abilities?
☐ usually ☐ sometimes ☐ rarely

4. Does client underestimate behavioral changes?
☐ usually ☐ sometimes ☐ rarely

SECTION TWO: Worker Trait Factors

A. Functional Reasoning Level (check one)

☐ 0 Does not use common sense, cannot follow simple instructions.
☐ 1 Uses common sense, follows 1-2 step instructions in tasks with no variability.
☐ 2 Uses common sense, follows simple written and oral instructions, minimal variability in tasks.
☐ 3 Uses common sense, interprets instructions in written or diagram form, deals with several concrete variables.

☐ 4 Solves practical problems within preexisting structure, deals with several concrete variables with limited standardization, interprets directions in all modalities.

☐ 5 Defines problems, collects data, establishes facts, draws valid conclusions, interprets extensive instructions in any format, deals with both abstract and concrete variables.

☐ 6 Applies logical or scientific thinking to solve wide range of abstract problems, may involve formulas and equations.

B. Physical Capacities/Sensory Modalities

1. Status of motor system? (check all that apply)

☐ hemiparesis ☐ right ☐ left
☐ hemiplegia ☐ right ☐ left
☐ paraplegia
☐ quadriplegia
☐ ataxia
☐ apraxia

2. Problems noted in visual acuity? ☐ yes ☐ no

3. Problems noted in perception?

visual scanning? ☐ yes ☐ no
form perception? ☐ yes ☐ no
clerical perception? ☐ yes ☐ no

4. Visual fields intact? ☐ yes ☐ no
If no, specify ______________________________

5. Does client have inattention to visual field (visual neglect)?
☐ yes ☐ no

If yes, ☐ right ☐ left ☐ subtle ☐ apparent

---

6. Problems with hearing? ☐ yes ☐ no
7. Problems with sensation/touch? ☐ yes ☐ no
8. Problems with sense of smell or taste? ☐ yes ☐ no

C. Language skills

1. Receptive - Understands simple 1-2 step verbal instructions?
   ☐ usually ☐ sometimes ☐ rarely

2. Expressive - Expresses basic needs (e.g. food, water, toileting)?
   ☐ usually ☐ sometimes ☐ rarely

   Expresses more complex ideas (e.g. social relationships, abstract concepts)?
   ☐ usually ☐ sometimes ☐ rarely

For the next sections circle the applicable rating based on the following scale, where appropriate

1 Top 10% of general population
2 Top third of general population (exclusive of top 10%)
3 Middle third of general population
4 Bottom third of general population (exclusive of bottom 10%)
5 Bottom 10% of general population

3. Reading recognition	1	2	3	4	5
4. Reading comprehension	1	2	3	4	5
5. Written spelling	1	2	3	4	5

D. Math skills

1. Calculation	1	2	3	4	5
2. Numerical reasoning	1	2	3	4	5

E. Motor Execution

1. Eye-hand coordination	1	2	3	4	5
2. Finger dexterity					
left	1	2	3	4	5
right	1	2	3	4	5
both	1	2	3	4	5
3. Manual dexterity					
left	1	2	3	4	5
right	1	2	3	4	5
both	1	2	3	4	5

4. If the above ratings are below average, is this due to:

slowness? ☐ yes ☐ no
inaccuracy? ☐ yes ☐ no

5. Reaction time - upper extremities
☐ impaired ☐ not impaired

SECTION THREE: Behavioral Observations

1. Appropriate social interaction?
☐ usually ☐ sometimes ☐ rarely

2. Appropriate frustration tolerance?
☐ usually ☐ sometimes ☐ rarely

3. Appropriate dress?

☐ usually ☐ sometimes ☐ rarely

4. Appropriate hygiene?
☐ usually ☐ sometimes ☐ rarely

5. Punctual, e.g., for appointment and returning from breaks?
☐ usually ☐ sometimes ☐ rarely

6. Dependable, e.g., scheduled and kept appointments?
☐ usually ☐ sometimes ☐ rarely

7. Annoying habits?
☐ usually ☐ sometimes ☐ rarely

8. Disinhibition

verbal? ☐ usually ☐ sometimes ☐ rarely
physical? ☐ usually ☐ sometimes ☐ rarely
sexual? ☐ usually ☐ sometimes ☐ rarely

SECTION FOUR: Recommendations

1. Recommend return to preinjury job? ☐ yes ☐ no ☐ unable to judge ☐ NA

If yes, estimate time to return to work ______________________________

2. Is further recovery expected? ☐ yes ☐ no

Over what time period?______________________________

3. Is further rehabilitation recommended? ☐ yes ☐ no

If yes, check what is recommended:
☐ medical consultation
☐ occupational therapy consultation
☐ psychological/psychiatric services
☐ physical therapy consultation

☐ case management/social services
☐ independent living evaluation
☐ speech/language therapy
☐ educational services
☐ driving evaluation
☐ vocational assessment
☐ vocational counseling
☐ cognitive training
☐ behavioral training
☐ work adjustment services
☐ therapeutic recreation services
☐ supported employment/job coaching services
☐ substance abuse screening/treatment

Is counseling recommended? ☐ yes ☐ no

If yes, check type ☐ individual ☐ marital ☐ family

4. Supervision needed in competitive job for:

Behavioral problems?	☐ yes	☐ no
Cognitive difficulties?	☐ yes	☐ no
Physical limitations?	☐ yes	☐ no
Other?	☐ yes	☐ no

Suggested Neuropsychological Tests For Each Area

Attention / Concentration / Processing

Behavioral Observations
Immediate Auditory Attention Span (WMS-R)
Visual Attention Span (WMS-R)
Paced Auditory Serial Addition Test (PASAT)
Digit Cancellation
Visual And Auditory Vigilance Tasks (Identification Of Targets From Distractors Over Time)
Trails A & B
Digit-Symbol (WAIS-R)
Symbol-Digit Modalities Test (SDMT)

Problem Solving

Wisconsin Card Sorting Test (WCS)
Halstead Categories Test
Similarities (WAIS-R)
Proverb Interpretation
Block Design (WAIS-R)

Memory

Wechsler Memory Scale-Revised (WMS-R)
Buschke Verbal Selective Reminding Procedure
Rey-Auditory Verbal Learning
California Verbal Learning Test (CVLT)
Hannay Continuous Visual Recognition Memory Test
Trahan Larrabee Continuous Visual Recognition Memory Test
Rey-Osterieth Complex Figure
Benton Visual Retention Test
Warrington Recognition Memory Test
Kimura Figures
Rivermead

Insight

Behavioral Observations
Interview
Neurobehavioral Rating Scale (NRS)

Functional Reasoning

WAIS-R
Shipley
Raven's Progressive Matrices
Test Of Non-Verbal Intelligence (TONI)
Mini Mental Status Examination (MMSE)

Sensory

Visual Acuity Screen
Visual Fields Screen
Visual Hemispatial Extinction Screen
Line Bisection
Benton Form Discrimination
Benton Facial Recognition
Benton Judgement Of Line Orientation
Hearing Screen
Tactile Form Perception
Finger Localization
Graphesthesia
Stereognosis

Language

Multilingual Aphasia Examination
Boston Diagnostic Aphasia Examination
Western Aphasia Battery
Neurosensory Center Examination For Aphasia

Written Language

WRAT-R (Reading & Spelling)
Subsets Of Above Tests
Reading Comprehension From The PIAT
Subsets From The Woodcock - Johnson
Gray Oral Reading Test

Math

WRAT-R (Arithmetic)
Arithmetic Subtest WAIS-R
Subtest Of Woodcock-Johnson

Motor

Grip Strength
Finger Tapping
Grooved Pegboard
Purdue Pegboard

Section L

Driving Evaluations

Driving Evaluations

Goals

An increasing number of persons with moderate to severe traumatic brain injury (TBI) in the United States as well as other countries are left with permanent disabilities as a result of their injuries. These injuries also account for an estimated 4.1 million pre-retirement years of disability. This situation results in a large number of young persons with TBI being unable to perform many activities related to independent living, one of the most important being the operation of a motor vehicle.

There are, however, large numbers of persons with brain injuries who are "back on the road again," but who have never been evaluated or received rehabilitation for their driving skills after receiving a brain injury. This section will discuss an Adapted Driving Program model and give some recommendations for adaptive evaluation and training.

Objectives

1. To present an hierarchical executive model of motor vehicle operation.
2. To discuss the assessment process of the Adapted Driving Program.
3. To describe the components of the Adaptive Driving Program (use of computer simulation and driver training).
4. To make recommendations regarding using the Adaptive Driving Program.

Resources for Driving Evaluations

Articles and Books

American Medical Association. Medical Conditions Affecting Drivers. Chicago, IL: American Medical Association; 1986.

Brooks N, et al. Driving Evaluation After Traumatic Brain Injury. American Journal of Physical Medicine and Rehabilitation. 1992; 71:177-182.

Gouvier, et al. Psychometric Prediction of Driving Performance Among the Disabled. Archives of Physical Medicine and Rehabilitation. 1989; 69:745-750.

Hopewell CA, van Zomeren AH. Neuropsychological Aspects of Motor Vehicle Operation. In: Tupper DE, Cicerone KD, eds. The Neuropsychology of Everyday Life. 1988.

Hopewell CA. Adaptive Driving After TBI. In: Burke W, et al, eds. The HDI Professional Series on Head Injury. Houston, TX: HDI Publishers; 1988.

McNeny R. Daily Living Skills: The Foundation of Community Living. In: Kreutzer J, Wehman P, eds. Community Integration Following Traumatic Brain Injury. Baltimore, MD: Paul H. Brookes; 1990.

van Zomeren AH, Bouwer WH, Minderhoud JM. Acquired Brain Damage and Driving: A Review. Archives of Physical Medicine and Rehabilitation. 1987; 68:697-705.

Driving Evaluation Issues for Persons with Traumatic Brain Injury

Most of our Activities of Daily Living (ADLs) are overlearned functions which are actually quite resistant to deterioration or impairment by organic brain syndromes. The basic components of driving are certainly overlearned (one starts the car as well as uses the gears and pedals automatically). Also, because these are the skills easiest to test, an evaluation of these operations as performed by the brain-injured driver may lead the naive therapist or observer to overestimate driving ability. The paradox is that while the operation of a motor vehicle requires adequate basic psychomotor competence for overlearned tasks, traffic participation simultaneously demands a great deal of flexibility and executive processing in order to cope with even routine traffic situations. Driving, therefore, never becomes completely routine.

Driving behavior in traffic may be regarded as an hierarchically organized set of tasks with three levels:

1. Strategic
2. Tactical
3. Operational.

At the "strategic" level, driving decisions are made generally without time pressure and involve choices such as route to be taken and time of day in which driving will occur. "Tactical" decisions are made on the road, involve slight time pressure, and usually involve judgements such as when to slow down or switch on headlights during periods of poor visibility. The strategic and tactical levels of functioning, especially, require the ability to anticipate, and judge consequences. The "operational" level involves the numerous perceptions and actions during driving and contains a constant demand of time pressure. Salient identified operational problems include poor visual scanning, spatial and orientation dysfunction, poor tracking, motor retardation, confusion in complex or simultaneous demand situations, and poor coordination of the lower extremities.

An important aspect of this three-level model is contained in a concept of an hierarchical structure. Decisions on a higher level determine to a large extent the workload on lower levels. For example, the strategic decision to avoid rush-hour traffic will result in fewer decisions and actions to be taken at the tactical and operational levels. Likewise, the tactical decision to increase speed will place higher demands upon the operational level in terms of tracking ability and quick responses to unexpected situations. This hierarchical nature can also be referred to as top-down control.

Mental functions most important at the strategic and tactical levels of driving are the executive and control functions of the human brain. Such functions are especially related to the planned control of action at lower levels as well as the anticipation of events. These executive functions also play an important part in resistance to distraction as well as the mental flexibility to switch attention, yet return to higher-order task goals.

Faced with daily practical decisions regarding the return to driving of TBI survivors being discharged from acute rehabilitation, Hopewell and Price (1985) undertook a three-tiered study of the problem. A total of 30 (53%) of acute rehabilitation patients who improved enough to be referred to the Adaptive Driving Program were eventually able to return to motor vehicle operation. Analysis of reasons for failure to return to driving included persistent visual problems, motor difficulties necessitating assisting devices for mobility, and topographical disorientation. Further investigation demonstrated that patients showing an estimated IQ of 80 or less (as a direct result of the TBI), those failing a driver simulation test, those rated as significantly impaired on a driver rating scale, and those with post-traumatic amnesia lasting eleven or more weeks, were unable to resume driving. It was therefore suggested that these measures could serve as neuropsychological "markers" to differentiate those TBI patients able to return to driving from those who could not.

Practical Recommendations For Adaptive Evaluations And Training

The major recommendation for an Adapted Driving Program is to suggest a focus upon the complex executive abilities required for the operation of a motor vehicle and a team evaluation rather than a narrow focus upon basic component skills. The complex executive and personality functions of the driver should be systematically assessed, and therapy specifically directed toward these functions. Evaluations at the operational level should also include dynamic measures which are influenced by executive functions, rather than static measures, such as dynamic vision. For example, simple visual screening should be seen as appropriate only for disqualification of candidates failing this portion of the exam, and visual assessment must also include measures of visual tracking, peripheral competence, figure-ground competence, and other exams of dynamic vision. Specific personality disorders, such as premorbid characterological disorders or alcohol and substance abuse, should automatically disqualify the patient from immediate resumption of vehicle operations until successfully treated. In acute rehabilitation, preexisting psychiatric disorders are often diagnosed, many of which contributed directly to the original injury. Aside from substance abuse and characterological disorders, these are most likely to be manic-depressive illnesses, and, occasionally other psychotic or dementing disorders. A team approach emphasizing a neuropsychological model of function should therefore be employed, rather than reliance upon simple assessment of visual or motor abilities.

A number of computer programs as well as small vehicular simulators have been used to investigate driving skill and rehabilitation. There has been some evidence to show that training in small vehicle simulators may produce a therapeutic effect. The question of how much simulators have in common with standard size vehicles as well as how computer training generalizes remains important. Many investigators have concluded that either small vehicle or computer simulators currently have only moderate predictive ability for actual motor vehicle operation, and they appear to be of the most use in training specific skills or in helping patients, families, or staff gain insight into the neuropsychological deficits which would preclude driving. For example, some clients are clearly unable to drive, and yet they sometimes demonstrate strong denial, and refuse to work with the simulator to help with insight into their limitations with regard to safe operation of a motor vehicle.

Some centers have relied on computerized vehicles with complex features such as zero resistance steering. As those TBI patients who are able to drive require little, if any, such adaptive equipment, such vehicles are completely unnecessary with this population. Indeed, our experience has been that TBI or other neuropsychologically-impaired drivers are especially at risk with such vehicles because of the combination of poor functioning at the strategic, tactical, and operational levels. The sensitivity of such vehicles to over-steering or accelerator/braking maneuvers then creates a condition of high risk. Productive research with neuropsychologically-impaired individuals, especially given the cost of such vehicles, appears unlikely, although they remain useful for patients with only physical handicaps.

In considering the resumption of driving and the therapeutic facilitation of this goal, a multistage decision model is suggested. In such a model, each patient is tested initially for basic critical (marker) skills such as vision, motor ability, and deterioration in overall IQ. Failure on any of these tests, even if the failure is slight or all other tests are passed, results in disqualification of the driver. Therefore, failure of any of the neuropsychological markers (limiting factors) would disqualify driving. In addition to disqualifying those who do not meet minimum vision requirements or who continue to show evidence of seizure disorder, patients with a moderate or severe dementia; any patient with an IQ lower than 80 which has apparently deteriorated due to an acquired neurological condition; brain-impaired patients who require an assisting device for ambulation other than a cane or who would require adaptive devices other than a spinner knob or left foot pedal; those patients showing topographical disorientation; and patients demonstrating a severe level of impairment on standard neuropsychological batteries may be rejected. In addition, patients with severe premorbid characterological or other psychiatric disturbances, especially if contributing to the original injury, or alcohol/substance abuse, should be referred for evaluation and treatment of these disorders before proceeding with the Adapted Driving Program.

Neuropsychologists and driving instructors should insure successful completion of such appropriate treatment programs before proceeding with driver training.

Candidates passing such tests are then to be further evaluated in the clinic or laboratory. Those judged unsafe because of impaired executive processing, psychomotor functioning, personality, or other reasons may then also be rejected. Those passing the clinic or laboratory stage should be referred to the adaptive driving instructor for a combination of classroom and vehicular training. Upon completion of driving instruction, patients may be recommended for rejection, recommended to be allowed to drive with restrictions, or recommended to be allowed to drive without restriction. An interesting model at this stage is that the rehabilitation team may make a referral to a "mini-evaluation" team after routine staffing identifies the need for a driving evaluation. The members of this team are comprised of the neuropsychologist, driving instructor, occupational therapist, physical therapist, speech-language pathologist, and other members as needed. A "mini evaluation" is conducted, results are relayed to the overall rehabilitation team, and driving then assigned a priority rating in a problem-oriented record format. This may also be a good time to notify the state Medical Advisory Board, Department of Public Safety, of the patient's medical and cognitive status.

It should be noted that only *recommendations* should be made by rehabilitation personnel to the family as well as the Department of Public Safety at the conclusion of the Adapted Driver Program. Successful completion of adapted driving instruction should automatically lead to actual driver testing by the local Department of Public Safety as well as clearance by the state Medical Advisory Board. It should be emphasized that clearance for actual motor vehicle resumption should be given by the state Medical Advisory Board, with the role of the rehabilitation facility restricted to that of providing disposition recommendations. Neuropsychologists should request a written report of the patient's performance in the Adapted Driving Program, and both the examining neuropsychologist and adapted driving instructor should request a written report of results from the Department of Public Safety examination. Common restrictions might include prohibitions against freeway driving, driving at night, or driving except to work.

A typical assessment and rehabilitation paradigm should include the following:

1. Notification to state Medical Advisory Board of injury status by family or physician.

2. Rehabilitation staffing to determination possibility of Adaptive Driving referral and "mini evaluation".

3. Referral by physician and rehabilitation team to Adaptive Driving Program (some or all of the following tests may be performed either prior to, or subsequent to, such referral).

4. Vision testing, to include:

- Visual acuity
- Field of vision
- Depth perception
- Phoria
- Color perception
- Night vision
- Dynamic vision
- Glare vision
- Glare recovery.

5. Hearing screening.

6. Reaction time assessment.

7. Active range of motion.

8. Manual muscle test.

9. Functional strength.

10. Neuropsychological assessment, to include premorbid psychiatric evaluation.

11. Psychiatric, neurological, or substance abuse referral, if necessary.

12. Psychiatric/substance abuse/seizure clearance.

13. Simulator and/or small scale vehicle evaluation.

14. Full-scale vehicle evaluation.

15. Adaptive device prescription.

16. Driver education and training.

17. Family counseling.

18. Re-contact of the state Medical Advisory Board and/or notification of local Department of Public Safety.

19. Retesting by Department of Public Safety and clearance by the Medical Advisory Board with restrictions (if any).

20. Neuropsychologist or rehabilitation team should also request periodic retest.

Recommendations for driving, as well as the attention of the treatment team as a whole, should also be discussed with the immediate family. Unfortunately, when families communicate with rehabilitation personnel regarding the advisability of the resumption of driving, the conversation often resembles either a testimonial to the presumed therapeutic benefits of motor vehicle operation, or an interaction with a family member who has difficulty grasping the concept of risk involved, presumably due to the powerful effects of denial. Arguments are often encountered such as "It will help his coordination," "It will be good for his visual training," "It will help his self-image," and, "It will just kill her if she realizes she can't drive a car again."

Conversations such as these led to a review of therapeutic modalities recommended by the American Association of Physical Therapy as well as the American Psychological Association. Although there exist many different schools of thought regarding accepted principles of both physical and psychological therapy, the placement of a mentally-impaired individual in command of a motor vehicle is obviously not a recognized therapeutic technique of any such professional organization! The cultural myth that driving is a "right" when it is actually both a privilege and responsibility only adds to the counseling problem. Driving is therefore *never* to be recommended as a form or treatment, neither as a physical or a psychological therapy. A *risk-benefit consideration* is also advised in any decision model employed for the potential adaptive driving training of neuropsychologically-impaired individuals, and may be helpful in counseling families. This type of judgement of risk is also advised by the American Medical Association (1986). By risk-benefit consideration, the team and the family weigh the perceived benefit to driving resumption against the risk involved and come to a sensible conclusion. A young person, having his whole life before him, who has done well in other areas of rehabilitation, shows adequate judgement, and where driving may make the difference between getting to work or therapy, may indeed be judged as an acceptable risk (remember also that we may minimize, but never eliminate risk!). However, an older person who is not returning to work and has acceptable alternate means of transportation, who refuses to listen to family or rehabilitation professionals, and to whom motor vehicle resumption is more a psychological boost than a functional goal, should be viewed as demonstrating a significantly lower degree of benefit to the risk involved.

Driving programs should be carefully planned and integrated into the overall rehabilitation plan. The programs should require both a physical medicine (physiatry) exam as well as a neuropsychological evaluation in order to clear patients for participation in the program and should involve all members of the treatment team in the decision-making process. Instructors should preferably be rehabilitation professionals such as occupational therapists who have received formal training in driving instruction. A Policy and Procedure Guide or Standard Operating Procedure should be maintained by the hospital and responsible department. This procedural guide should specify:

1. Which patients may be referred and how these referrals are accomplished.
2. Mandatory neuropsychological examination of all patients referred for driver training.
3. Mechanism for recommendations regarding driving disqualification.
4. Mechanisms for referring patients to collateral examinations, such as ophthalmology or sleep/wake disorders assessment if necessary.
5. The goals and mechanisms of driving instruction.
6. Overall responsibility for the driving program.
7. Specification of how recommendations are made to the patient, to the family, and to the Department of Public Safety.
8. Development of a mechanism for authorization of relaying information to the state Medical Advisory Board or other appropriate agencies.
9. Clear indication that only recommendations are made to the family, patient, and Department of Public Safety, and that decisions regarding actual licensure are not made by the hospital but by the Medical Advisory Board.

Appendix

Slide Presentations:

Understanding Traumatic Brain Injury

Changing Attitudes: Addressing the Greatest Barrier to Independent Living

Sexuality and Brain Injury

UNDERSTANDING TRAUMATIC BRAIN INJURY

by

The Texas Head Injury Association

M.1

HEAD INJURY - a general term indicating damage to the head, including the skin covering the skull, bones of the skull, face or jaw, or to the contents of the skull.

M.2

BRAIN INJURY - a more specific term indicating damage to brain cells that causes temporary or permanent interruption in their functioning.

M.3

MECHANISMS OF INJURY TO BRAIN CELLS

- External Physical Force (Trauma)
- Insufficient Blood Pressure (Heart Attack)
- Interruption of Blood Supply (Stroke)
- Insufficient Oxygen in the Blood (Drowning)
- Toxic Substance in the Blood (Inhalant)
- Infection (Bacteria, Virus)

MECHANISMS OF INJURY TO BRAIN CELLS (continued)

- Secondary Damage
    - Biochemical (Free Radicals)
    - Mechanical (Swelling)
- Congenital Disorder (Developmental
- Birth Trauma (Cerebral Palsy)
- Malignancy (Tumor)
- Degenerative Process (Alzheimer's)

TRAUMATIC BRAIN INJURY (TBI)

Damage to the brain by physical force that results in impairment of one or more brain functions including:

- arousal
- orientation
- attention
- memory
- learning
- sensory abilities
- perceptual abilities
- motor abilities
- self-awareness
- psychosocial behavior
- information processing
- speech/language
- reasoning
- problem-solving
- abstract thinking

INCIDENCE

- 200 persons injured/100,000 population
- 30,000 to 40,000 Texans sustain brain injuries each year
- 500,000/year nationally (1 every 64 seconds)
- 70,000 to 90,000 permanently disabled

M.7

INCIDENCE (continued)

	Number per 100,000 Population
Moderate and Severe TBI	30
Aids	15
Cerebral Palsy	9
Multiple Sclerosis	3
Spinal Cord Injury	3
Muscular Dystrophy	1

RISK FACTORS

- Young (15-24 peak age)
- Male (2-3 times more frequent)
- Summer (June through September)
- Alcohol (55% related to use/abuse)
- Prior Psychiatric/Social Dysfunction
- Certain Jobs

M.9

POST TRAUMATIC AMNESIA (PTA)

The period following injury during which the patient does not have continuous daily memory of events.

Duration of PTA correlates significantly with impaired memory function later.

PROCESSING CHARACTERISTICS ASSOCIATED WITH TBI

1. **Impulsivity**
2. **Inability to process large amounts of information**
3. **Slow processing speed**
4. **Fatigue**

M.11

SEQUELAE OF CLOSED HEAD INJURY

Psychosocial, Behavioral, and Emotional Impairments

Psychosocial Problems	Behavior Problems	Emotional Problems
Dependency	Passivity	Emotional instability or lability
Affective disorders	Impulsivity	Low Self-esteem
Personality disorders	Childishness	Anxiety
Poor interpersonal relations	Sexual dysfunction	Depression
Social isolation	Lack of goal-oriented behavior	Unrealistic expectations
Neurosis	Inability of self-monitor	Low frustration tolerance
Psychosis	Inappropriate social behaviors	Disturbed self-image
Alcohol or drug abuse	Restlessness	Apathy
	Aggressiveness	Irritability
	Slovenliness	Denial of disability
	Loss of inhibitions	Egocentricity

Wehman P. Life Beyond the Classroom: Transition Strategies for Young People with Disabilities; 1992.

RECOVERY OF FUNCTION

May range from:

A few weeks
to
many years

M.12

REHABILITATION

The Process Of Helping Persons
Achieve Their Potential
to Function

M.13

PRE-INJURY FACTORS INFLUENCING RECOVERY

A. Medical

- Age
- General physical health
- No prior brain injury or CNS problems (i.e., infections, seizures)
- Minimal history of chronic disease (i.e., hypertension, diabetes)
- Normal developmental progression
- No prior psychiatric illness

M.15

PRE-INJURY FACTORS INFLUENCING RECOVERY (continued)

B. Educational

- High IQ with good school achievement
- No prior history of learning disability or special education
- Pre-injury job stability/reliability
- Well-developed technical skills

PRE-INJURY FACTORS INFLUENCING RECOVERY (continued)

C. Social

- Socially active with demonstrated social skills
- Ability of family to support; good relationship with parents; life structure
- No prior criminal history
- No history of substance abuse
- Community support and financial resources
- Stable marital/social relationships

POST INJURY FACTORS AFFECTING RECOVERY

- Coma less than 6 hours
- Post traumatic amnesia less than 24 hours
- Glasgow Coma Scale score greater than 7
- No intracranial bleeds, infections, or post traumatic seizures
- Minimal brain swelling and absence of herniation
- No hypoxia/anoxia
- Insight into deficits

OUTCOMES

- Severely impaired - only 5% are able to achieve and hold a paying job
- Moderately impaired - 34% return to prior work
- Mildly impaired- 66% are back to work within 4 months (mild TBI patients more likely to develop psychiatric symptoms)

FINANCIAL IMPACT

- Average cost of initial hospitalization and rehabilitation is $118,000

- Family will be billed an estimated $4.5 million over a lifetime

- Who Pays:
  - Insurance - 48%
  - Government - 40%
  - Unpaid (Indigent care) - 6%
  - Self Pay - 4%
  - Other - 2%

PREVENTION IS THE ONLY "CURE"

ACCIDENTS DO NOT JUST HAPPEN

**Injuries are caused by specific behaviors,
and are preventable**

LIFE SAVING BEHAVIORS

- Abstain from alcohol when driving
- Use lap and shoulder seatbelts
- Buy cars with air bags
- Wear helmets when riding bicycles or motorcycles. Helmets should be certified by ANSI or Snell

LIFE SAVING BEHAVIORS (continued)

- If you must have firearms, store them and lock them safely
- Check the depth of water before diving
- Install adequate lighting and handrails, especially in stairways

CHANGING ATTITUDES:

ADDRESSING THE GREATEST BARRIER TO INDEPENDENT LIVING

by

The Texas Head Injury Association

M.24

OBVIOUS BARRIERS

- Inadequate & underfunded services
- Inaccessible environments
- Segregated programs
- Lack of opportunities

M.25

ATTITUDINAL BARRIERS

- Stereotypes
- Myths
- Language
- Social Values & Roles
- "Disability Model"

M.27

ROOTS OF PREJUDICE: EARLY GREEK, CHRISTIAN AND HEBREW BELIEFS

- Persons with physical/mental disabilities are inferior
- Demon possessed
- Punished by God
- Should be isolated or shipped out to sea

ROOTS OF PREJUDICE: MIDDLE AGES BELIEFS AND PRACTICES

- "Handicap" = Begger
- Housed in large asylums

ROOTS OF PREJUDICE

- Traditional medical model - treatment and cure
- Professional as sole expert
- Disability = dependency, sickness
- Able-bodied values = "Normal"

DISABILITY RIGHTS MOVEMENT

- Demand access and equality
- Determined to take their place in society
- Eliminating stereotypes and myths

LANGUAGE AS A BARRIER

- Avoid "the disabled" and "the handicapped"
- Avoid putting disability before person (blind man, deaf woman)
- Avoid "victim of", "suffers from", "confined to"
- Use "PEOPLE FIRST" language

LANGUAGE ABOUT TRAUMATIC BRAIN INJURY

M.32

NEGATIVE WORDS

- "Crazy", "Stupid", "Weird"
- "Vegetable"
- "Brain Damaged", "Brain Dead"

USE INSTEAD

- "Person with Traumatic Brain Injury" (TBI)

M.33

SEXUALITY AND BRAIN INJURY

by
Vikki Stefans, MD, MS

BRAIN INJURY

- Medical
- Neuropsychological
- Normalization & empowerment
- Exploitation & safety
- Sexual discrimination in rehabilitation
- Sexuality and disability

MEDICAL ISSUES

M.35

NEUROENDOCRINE

HYPOPITUITARISM

- Infertility
- Decreased sex drive and performance

HYPOTHALAMIC INJURY

- Precocious puberty in children

MEDICAL ISSUES

Medication Side Effects

- Anti-hypertensives - decreased sex drive
- Seizure medications - vary
- Sedatives - decreased sex drive and performance
- Consider risks of medication during pregnancy

SEIZURE MEDICATIONS

M.37

	SEXUALITY EFFECT	PREGNANCY RISK
PHENOBARBITAL	-	+
DILANTIN	—	++
TEGRETOL	varies	+
DEPAKENE	+	++
FELBAMATE & NEWER DRUGS	?	?
UNCONTROLLED SEIZURES		+++

FOCUS ON HYPERSEXUALITY IN LITERATURE

- Disinhibition (Frontal Lobe)
- Increased drive, insatiability (Bilateral deep temporal lobe - Kluver-Bucy)
- Memory problems - repeated or constant demands

Focus On Correcting Overt Problem Behavior In Practice

BUT...

1 - 10% post-injury have excess or inappropriate sexual behavior

58 - 75% post-injury have reduced sexual interest and function

NEUROPSYCHOLOGICAL CAUSES OF REDUCED SEXUAL INTEREST AND FUNCTIONING

M.40

- Emotional: Stress, anxiety, depression
- Fatigue
- Communication difficulties with partner:
  - anomia
  - aphasia

NEUROPSYCHOLOGICAL CAUSES OF REDUCED SEXUAL INTEREST AND FUNCTIONING (continued)

M.41

- Changes in social behavior
- Changes in relationships
- Changes in role

TAKING A SEXUAL HISTORY

- Do one in all cases
- Target pre-morbid functioning
- Target loss of interest or functioning
- Give permission to talk about it further

M.42

"It's too early, wait another six months..."

"Wait another year",

and then

"We'll talk about it another time."

....When is that time going to come?

INCREASED SEXUAL INTEREST

... the employee pinches the clerk as he walks by

... the employee makes off color remarks or sexual innuendoes

... the employee posts or circulates sexually demeaning jokes or cartoons in the office

M.44

CAUSED BY TBI?

- Behaviors are common in young, particularly poorly socialized males
- Young, poorly socialized males commonly engage in risk-taking behaviors that predispose to TBI

CAUSED BY TBI?
(continued)

- **Behaviors less tolerated in workplace, more quickly labeled sexual harassment, but still occur**

MANAGEMENT

- Environmental modification
- Modeling appropriate behavior
- Peer counseling
- Behavior modification

(Pre-morbid, post-morbid or "just morbid" .... you still may be fired!)

M.47

M.48

AVOID RESTRICTION EXCEPT

- Invasion of others' privacy
- Non-mutually consenting activity
- Private behaviors in public
  (private space must be available)

PLISSIT MODEL

- Permission
- Limited information
- Specific suggestions
- Therapy (refer)

M.49

PERMISSION / INFORMATION

- Reframing, de-mystifying for spouse
- Problems are common -
  can / should be addressed
- Rights to sexuality as an adult
- Rights to sexuality for person with a disability

SUGGESTIONS / THERAPY

- Medical evaluation & treatment
- Specific techniques / devices to accommodate physical disability
- Modify environmental factors
- Promote self-esteem & socialization
- Formal referral to sex therapist

SEXUAL ASSESSMENT PLANNING

- **Kenneth Lefebre, PhD (R.I.C.)**
- **Scores +, -, or ?**
- **If more +, proceed**
- **If more -, address underlying issue first**

(Journal of Head Trauma Rehabilitation. 1990; 5(2):25-30.)

ADULT DEVELOPMENTAL MILESTONES

M.53

- Working
- Living independently
- Driving
- Dating
- Parenting

SEXUAL DISCRIMINATION

- Women are more likely to be placed in nursing homes
- Males are less likely seen as able caregivers
- Females are less often referred for driving evaluations, and are offered less challenging / stereotyped rehab activities or vocational choices

FEMALE SEXUALITY ISSUES OFTEN NEGLECTED

- Intimacy
- Decreased desire & function
- Pregnancy, fertility, & contraception
- Sensory aspects - pleasure, orgasm

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